Chapter 4

Assistance and support for veterans

Introduction

4.1 An area of unanimous agreement in this inquiry is the utmost importance of individuals who are unwell being able to access appropriate support and assistance. The role of both the Department of Defence (Defence) and the Department of Veterans' Affairs (DVA) in offering and providing support and assistance was a key focus in much of the evidence received by the committee.

4.2 The committee spoke with some veterans who were clearly in need of immediate assistance and many of these individuals had been trying to access support for some time. As noted earlier in the report, the committee was pleased that representatives from DVA were in attendance at hearings and available to provide assistance and support to individuals and families in immediate need if they wished to speak with them.

4.3 This chapter discusses the matters raised with the committee in relation to the provision of assistance to veterans, with particular reference to assistance with their health concerns. It covers the actions taken to date by Defence and DVA; veterans' experiences with accessing assistance; barriers to accessing assistance; the assistance and support being sought; and addressing veterans' concerns moving forward.

Summary of Government actions to date

4.4 As noted in Chapter 1, this committee tabled the report, titled *Mental health of Australian Defence Force members and veterans*, on 17 March 2016. The report included two recommendations in relation to mefloquine.[1]

4.5 Responding to the committee's recommendations from the report, on 15 September 2016, the Minister for Veterans' Affairs, the Hon Dan Tehan MP announced that the government would:

- establish a formal community consultation mechanism to provide an open dialogue on issues concerning mefloquine between the Defence Links Committee and the serving and ex-serving ADF community;
- develop a more comprehensive online resource that will provide information on antimalarial medications;
- establish a dedicated DVA mefloquine support team to assist our serving and ex-serving ADF community with mefloquine-related claims, which will provide a specialised point of contact with DVA; and

1 Senate Foreign Affairs, Defence and Trade References Committee, *Mental health of ADF serving personnel*, 17 March 2016. See Recommendations 5 and 6.

- direct the inter-departmental DVA-Defence Links Committee to examine the issues raised, consider existing relevant medical evidence and provide advice to the Government by November 2016.[2]

4.6 With particular reference to these actions identified by the Minister for Veterans' Affairs, the committee asked witnesses at its public hearings in Brisbane and Townsville for their perspective on the progress of recommendations. While noting that witnesses would likely be unaware of the DVA-Defence Links Committee action, it was disappointing to note that several witnesses indicated they were completely unaware of the other actions.[3]

4.7 Following the hearing, Senator Alex Gallacher wrote to the Minister for Veterans' Affairs, the Hon Darren Chester MP, seeking advice on the progress of the announcements from the Government.

4.8 On 18 September 2018, the Minister wrote to the committee and included the following update:

> With respect to the commitments made by the then Minister for Veterans' Affairs, the Hon Dan Tehan MP, I can advise these have either been met or are ongoing. I draw the Committee's attention to the submission to the inquiry from DVA which provides more information about services and supports available to veterans and their families; and the future action plan involving further outreach, communications and research in this area.[4]

4.9 While it is disappointing that there was little awareness of the response to the recommendations within the community the actions were designed to assist, the committee is aware that Defence and DVA have both undertaken a series of key actions in response to the issues and concerns raised about antimalarial use which are outlined below and throughout the chapter.

Department of Defence response

Key message

4.10 Defence has indicated that its response to concerns about the use of antimalarial drugs has 'been designed to provide current and former serving members with information about the medications of concern, detail on the studies, and to encourage them to seek help'.[5] A key message from Defence has been to encourage

2 The Hon Dan Tehan MP, Minister for Veterans Affairs, 'Addressing mefloquine concerns', *Media Release*, 15 September 2016.

3 Mr Greg Jose, *Committee Hansard*, 31 August 2018, p. 3; Mr Colin Brock, *Committee Hansard*, 31 August 2018, p. 8; Mr Wayne Karakyriacos, *Committee Hansard*, 31 August 2018, p. 8.

4 Correspondence from Minister for Veterans' Affairs, The Hon Darren Chester MP, response to Committee Chair, received 18 September 2018.

5 *Submission 1*, p. 30.

individuals with concerns to consult their treating medical practitioner and to consider putting in a claim with DVA.[6]

4.11 On 30 November 2015, Defence issued a statement on the use of mefloquine in the ADF and advised that 'if any ADF member, past or present is concerned that they might be suffering side-effects from the use of mefloquine defence encourages them to raise their concerns with a medical practitioner so they may receive a proper diagnosis and treatment'.[7]

Comprehensive website

4.12 In February 2016, VADM Griggs told the Senate Foreign Affairs, Defence and Trade Legislation Committee about the need for their actions to balance the provision of information with the need to avoid causing undue concern for people who are well:

> I would like to make the point that we are now in about month 7 of a pretty sustained media campaign about mefloquine. What we have been trying to do is to get out as much information as possible in as transparent a manner as possible to allay the fears of serving and former serving members of the ADF about the use of this drug, because the nature of the reporting and the nature of this campaign has elevated concern levels amongst people who do not need to be as concerned as they now are. We are actually quite concerned about that. One of the things we have just completed is a series of web pages, which is now available on the Defence internet site, which I think is a very comprehensive and transparent articulation of all the issues around antimalarials, not just mefloquine, in use in the ADF.[8]

4.13 In order to provide information to concerned veterans and their families, Defence developed a comprehensive external website on malaria, mefloquine and the ADF and established an email address where individuals can request further information.[9]

Information for families

4.14 Defence advised that information for families concerned about antimalarial use continues to be available by contacting the dedicated email address as well as accessing information from their website.[10]

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6 Department of Defence, *Submission 1*, p. 3.

7 See https://news.defence.gov.au/media/media-releases/statement-use-mefloquine-adf, accessed 27 June 2018.

8 VADM Ray Griggs, VCDF, Senate Foreign Affairs, Defence and Trade Legislation Committee, *Estimates Hansard*, 10 February 2016, pp. 173-174.

9 See http://www.defence.gov.au/health/healthportal/malaria/default.asp, accessed 16 July 2018. See also http://www.defence.gov.au/Health/HealthPortal/Malaria/Documents/160402%20-%20Townsville%20forum.pdf, accessed 16 July 2018.

10 *Submission 1*, p. 43.

4.15 In its submission Defence also described other support services available to families for a variety of reasons and not specifically related to concerns about antimalarial use such as the ADF Family Health Program, the All-hours Support Line, the Defence Family Helpline and the Veterans and Veterans Families Counselling Service (VVCS).[11]

Research

4.16 To inform its ongoing response to these issues, Defence has undertaken or commissioned research into a number of matters relating to its use of antimalarials and in particular mefloquine, including:

- a review of Medical Employment Classification outcomes of those who participated in the Timor-Leste trials. This has shown no significant differences in the incidence of becoming medically unfit for service, or diagnosis of PTSD between those who were prescribed mefloquine and those prescribed other anti-malarial medications;[12]
- a comprehensive literature review on mefloquine commissioned from Professor Sandy McFarlane AO, Director of the University of Adelaide Centre for Traumatic Stress Studies;[13] and
- commissioned (jointly with DVA) the University of Queensland to undertake a research study involving the re-analysis of health study data on anti-malarial use from the 2007-2008 Centre for Military and Veterans' Health deployment health studies.[14] Further information on this is outlined below.

Department of Veterans' Affairs response

Mefloquine support team

4.17 In accordance with the government commitment announced in September 2016, DVA established a dedicated mefloquine support team within their claims area to respond to inquiries about mefloquine. DVA advised the committee that the team 'did not receive many calls' and that team was subsequently put onto other duties within the claims area. In September 2018, DVA added information to their phone line, prompting callers to dial zero to speak to someone in relation to mefloquine but again they did not receive many calls.[15]

Support for GPs

4.18 DVA has provided information to general practitioners (GPs) to assist them to provide support to veterans who may have concerns about mefloquine:

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11 *Submission 1*, p. 44. VVCS is now called Open Arms—Veterans and Families Counselling.

12 Defence, *Submission 1*, p.42.

13 http://www.defence.gov.au/Health/HealthPortal/Malaria/Documents/160822-Mefloquine-and-suicide.pdf, accessed 16 July 2018.

14 DVA, *Submission 2*, p. 6.

15 Ms Cosson, *Committee Hansard*, 11 October 2018, p. 63.

- DVA's Principal Medical Adviser wrote to all GPs on 30 September 2016 and to the Primary Health Network in October 2016 to bring information about mefloquine to their attention;[16] and
- DVA organised and hosted a briefing with GPs in Townsville on 29 November 2016.[17]

Information event

4.19 In December 2016, DVA held an event, referred to as an 'outreach program',[18] in Townsville which was attended by more than 90 members of the community concerned about antimalarial medications such as mefloquine. Defence supported this event.[19] As noted earlier, the government committed to establishing a formal community consultation mechanism on issues concerning mefloquine and the Townsville 'outreach program' was the first step.[20]

Support for families

4.20 DVA provides support to veterans' partners and families through funding a range of health services as well as the front line mental health services provided through Open Arms—Veterans and Families Counselling (formerly VVCS).[21]

DVA's Future Action Plan

4.21 In its submission, DVA noted it has 'prepared an action plan to address [veteran] community concerns about potential effects of mefloquine that includes outreach activities, communications and research'.[22] Following the outreach program conducted in Townsville in December 2016 (in collaboration with the Repatriation Medical Authority (RMA), VVCS and with the support of Defence), DVA is conducting consultation forums across other capital cities. The submission noted that these will be publicised through advertisements in newspapers and services newspapers, as well as direct invitations to relevant organisations, and individuals where possible.[23]

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16 DVA, *Submission 2*, p. 5.

17 Defence, response to journalist, 6 December 2016, http://www.defence.gov.au/Health/HealthPortal/Malaria/Resources/media-statements.asp, accessed 16 July 2018.

18 Note: Veterans were very clear with the committee that they did not see this event as fitting their definition of 'outreach'. Detailed later in this chapter the committee heard about the next series of consultation forums being held by DVA.

19 *Submission 1*, pp. 31, 35.

20 See https://www.dva.gov.au/about-dva/publications/vetaffairs/vol-33-no1-autumn-2017/townsville-mefloquine-outreach-program, accessed 19 July 2018.

21 *Submission 2*, pp. 45.

22 *Submission 2*, p. 5.

23 *Submission 2*, p. 5.

4.22 Ms Liz Cosson AO CSC, Secretary, DVA, provided further detail about these consultation sessions at the hearing in Canberra. A series of sessions were planned in different locations throughout October and November. Further sessions in different locations would be considered should there be sufficient demand.[24] These consultation forums are further discussed later in the chapter.

DVA funded health treatment and compensation claims

4.23 The support provided to veterans who have been injured or suffered illness as a result of their service (including illness or injuries related to antimalarial medication) fall broadly into three categories—compensation, income support and health treatment. To access compensation and income support, a veteran needs to make a claim and show to the relevant standard of proof that they have suffered an illness or injury, and demonstrate that this condition was related to their service.[25]

4.24 In relation to health treatment, there are two pathways by which veterans may access DVA-funded services:

- Under the *non-liability pathway*, veterans can apply for access to treatment for mental health conditions without the need to show that the condition is related to service.
- Under the *liability pathway*, veterans can make a claim which DVA will then assess to establish whether the condition was related to service. If the claim is accepted, the veteran's entitlement to compensation and income support will then be assessed, and the veteran will be eligible for DVA-funded health treatment for the condition.[26]

4.25 In addition, all former serving personnel can access a comprehensive health assessment from their GP.[27] Independent of the claims process, mental health services are also available from Open Arms—Veterans and Families Counselling to all current and former serving personnel.[28]

4.26 Serving and ex-serving ADF members can claim compensation at any time for medical conditions they believe are related to their service. For DVA to accept liability for compensation there has to be a causal link determined between the person's service and their medical conditions. Under the *Veterans' Entitlements Act 1986* (VEA) and the *Military Rehabilitation and Compensation Act 2004* (MRCA) the potential link between a medical condition and service is assessed using Statements of Principles (SOPs).[29] SOPs are discussed later in this chapter.

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24 *Committee Hansard*, 11 October 2018, p. 64.

25 DVA, *Submission 2*, p. 2.

26 DVA, *Submission 2*, pp. 2–3.

27 DVA, *Submission 2*, p. 3.

28 DVA, *Submission 2*, p. 4.

29 RMA, *Submission 4*, p. 4.

Veterans' experiences with accessing assistance

4.27 The committee explored with individuals their experiences of accessing assistance; whether they had tried to access assistance, and if so, the details of that experience. The committee also spoke to veterans who had not accessed assistance and explored the reasons why not, as well as the assistance they are seeking.

Veterans who are accessing services and receiving help

4.28 Some individuals appeared to be accessing assistance. While acknowledging it had taken some time to access, Mr Mark Armstrong described the services he is receiving:

> I have access to a neurologist and a neuropsychologist, a psychiatrist and a psychologist because of my PTSD tag, so I'm able to get certain treatments through that. Other things like my brain injury—my eighth cranial nerve is 31 per cent more damaged on my right-hand side than on my left-hand side. As I was walking, I'd fall to my right, so I went and got that tested. That was through the PTSD as well. I suppose I'm one of the lucky ones—because I have a TPI [Totally and Permanently Incapacitated] gold card I have access to a lot of different medical things that other people don't.[30]

4.29 Another submitter explained their experience as follows:

> My health conditions are accepted by DVA and I consider I have been well looked after with treatment, hospitalisation and incapacity payments. My military super was converted to an invalidity pension at discharge. None of my accepted conditions contain reference to Mefloquine although my medical documents do so.[31]

Families/partners

4.30 A small number of partners and family members also advised that they have accessed some support services through DVA, including counselling services from Open Arms.[32] While some indicated that support had been of some assistance, others reported that the experience had not been helpful.[33]

4.31 However, Mrs Susan Armstrong spoke positively about her participation in the Female Veterans and Families Forum. While she noted there is limited opportunity to discuss personal circumstances in detail due to the number of issues in these forums, it did provide an opportunity 'to get to [speak to] someone in a meeting break'.[34]

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30 *Committee Hansard*, 30 August 2018, p. 12.

31 Name withheld, *Submission 61*, p. 1.

32 See for example Mrs Mary Bush, *Proof Committee Hansard*, 5 November 2018, p. 15.

33 See for example Mrs Susan Armstrong, *Committee Hansard*, 30 August 2018, p. 17.

34 *Committee Hansard*, 30 August 2018, p. 16.

Veterans who are getting assistance but believe it is not working

4.32 Some veterans explained that while they are receiving help, their current treatment and support has not been very successful in improving their health.[35]

4.33 Mr Stuart McCarthy explained that although some of his claims to DVA for issues such as depression and anxiety have been accepted, the available treatment predominately consisted of medication which has not been of great benefit.[36]

4.34 Mr Aaron King advised that he was classified as Totally and Permanently Incapacitated (TPI) some years ago and been diagnosed with PTSD but that the treatment he has received to date has not been effective:

> I'm TPI. I was made TPI years ago, not as a part of this [use of antimalarials]. We only just found out about this a couple of years ago, about the symptoms. It was put down to PTSD for me. I've got lots of side effects and problems. It's always just been put down to PTSD. Treatment-wise, there's Ward 17 at Heidelberg. Now they don't really want me to go, because they've exhausted all avenues. There's no treatment. I've had [Electroconvulsive Therapy and Transcranial Magnetic Stimulation] ECT, TMS [Transcranial Magnetic Stimulation] and pretty much every medication. I've been in and out of psych wards. I've been thrown in jail because they felt there was no other safe place for me at times.[37]

4.35 Mrs Naomi Kruizinga explained that the medications given to her husband, Mr Michael Kruizinga, have not helped:

> Many times before, Michael has been given a bandaid, or a temporary fix, to stop his suicidal ideation—more mood stabilisers under the PTSD umbrella—with most of his network of psychologists and psychiatrists linking it to just severe depression. Yet he suffers from the neurotoxic properties of these drugs that were given. None of the medications have worked since he commenced them over a year ago. If anything, they have made him worse.[38]

Veterans who are not receiving or seeking assistance

4.36 Worryingly, some veterans told the committee that they are not accessing help from DVA. In some cases, this was due to a lack of trust in the process. In other cases, it was suggested that veterans do not have a diagnosis and/or have not been able to access treatment and support because the effects of antimalarial medications are not recognised under a single SOP. This is further discussed later in the chapter.

4.37 Ms Anne-Maree Baker explained:

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35 Mr Chris Ellicott, *Proof Committee Hansard*, 5 November 2018, p. 49; Mr Aaron King, *Proof Committee Hansard*, 5 November 2018, p. 29; Mr Michael Bush, *Proof Committee Hansard*, 5 November 2018, p. 15.

36 *Committee Hansard*, 30 August 2018, p. 8.

37 *Proof Committee Hansard*, 5 November 2018, p. 29.

38 *Proof Committee Hansard*, 5 November 2018, p. 1.

> I have not used the phone lines and made claims for compensation with DVA because I am undiagnosed. None of my illnesses are attributed or connected to this trial because nothing has been reported correctly.[39]

4.38 Mr Stuart McCarthy told the committee that he has submitted claims for cognitive impairment which have not been accepted. Further to this, Mr McCarthy stated:

> …What's not happening—we are being refused the support (a) that we need and (b) that we have actually asked for. And that's exactly the situation that I'm in.[40]

4.39 Other veterans also discussed this issue. Mr Wayne Karakyriacos reported that '[a] lot of veterans have gone bush and a lot of them are hiding'.[41] Mr Desmond Rose told the committee that 'most of us don't contact DVA about tafenoquine anyway…'.[42]

4.40 One veteran, Mr Brian Carlon, is receiving assistance but reported that dealing with DVA is difficult:

> Everything I've done with DVA is a fight, and that fight takes its toll. I have nothing to do with DVA except: when they send me a letter, I will send it back. I don't ring them. I don't contact them. It's too hard on me, because it is a fight.[43]

Barriers to accessing assistance

4.41 As the committee was told that assistance is available and some witnesses described their experiences of positive support, the committee explored the reasons why some veterans are not accessing support. These include: ADF cultural issues, lack of information and difficulties navigating the claims process.

Cultural issues

4.42 As briefly noted in Chapter 3, some veterans suggested that the nature of the ADF environment means it is difficult to report health concerns or to question authority for fear of showing weakness and the potential impact on career progression.

4.43 On a similar theme, some veterans reported that it is difficult to ask for assistance. Colonel Ray Martin (Rtd) explained as follows:

> Certainly in my experience, and you've heard it today, men and women in the ADF are self-reliant and very well trained. They're kind of tough on the outside. As soon as they admit there's a mental health issue, even though

39 *Proof Committee Hansard*, 5 November 2018, p. 28.

40 *Committee Hansard*, 30 August 2018, p. 8.

41 *Committee Hansard*, 31 August 2018, p. 13.

42 *Committee Hansard*, 31 August 2018, p. 13.

43 *Proof Committee Hansard*, 5 November 2018, p. 24.

> the system says 'come seek help', the reality is you think that if you put up your hand there's a career detriment to that.[44]

4.44 Mr Rose told the committee that he has only recently started to seek support for PTSD due to the challenges of seeking help:

> It's something you don't like to admit. It's a bit hard, being a man and saying you've got mental problems. It's not the best.[45]

4.45 Mr Kruizinga acknowledged these cultural issues and suggested that there needs to be more assistance when a soldier transitions to civilian life.[46]

Lack of information

4.46 Mr Colin Brock reported that information about the trials has not been shared between Defence and DVA:

> I guarantee DVA doesn't know that we were on mefloquine or tafenoquine. How does DVA know? Defence hasn't told them. We haven't told them.[47]

Mefloquine support line

4.47 As outlined earlier in the chapter, DVA established a dedicated mefloquine support line to assist veterans who were concerned about antimalarials. Veterans and their families told the committee about their difficulties getting advice from this dedicated team.[48]

4.48 Mr Mark Armstrong explained his experience seeking information via the DVA dedicated mefloquine line:

> They [DVA] told me that they didn't have a list of mefloquine users and to contact the Department of Defence. They did give me a number for that, and the Department of Defence told me to contact DVA. So I contacted DVA, and we went back and forth a few times. There was supposed to be some special team that looked after it. Then, after a while, a lady rang me back, and she was in a special team—I think they call it a special team or something along those lines—who don't just look after mefloquine; they look after anything special.[49]

4.49 In a supplementary submission from the Australian Quinoline Veterans and Families Association (AQVFA), Mr McCarthy described his experience contacting the dedicated mefloquine support team in DVA. Mr McCarthy details two phone calls he made to the dedicated number in August and September 2018 seeking information

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44 *Committee Hansard*, 31 August 2018, p. 37.

45 *Committee Hansard*, 31 August 2018, p. 17.

46 *Proof Committee Hansard*, 5 November 2018, p. 5.

47 *Committee Hansard*, 31 August 2018, p. 13.

48 Mrs Raelene King, *Proof Committee Hansard*, 5 November 2018, pp. 30–31; Mr Mark Freer, *Proof Committee Hansard*, 5 November 2018, p. 48.

49 *Committee Hansard*, 30 August 2018, p. 15.

about the ADF use of tafenoquine. On both occasions, officers were unable to provide responses to questions. He reported:

> The 'dedicated mefloquine support team' was announced by DVA in 2016. The DVA Secretary has stated that this dedicated team and toll free number are part of her focus 'on the treatment for veterans who need assistance', however the staff of the 'dedicated mefloquine support team' do not hold contact information for healthcare providers and are unaware of the most basic, factual information regarding the ADF's use of mefloquine and tafenoquine.[50]

4.50 Following feedback from veterans, the committee was told that DVA made additional changes to the support line in October this year. The mefloquine support line is now answered by a team in Canberra that comprises:

> …some higher-level staff that actually understand the detailed nature of our SOPs and who can help any veteran that phones that dedicated line to assist with their claims—particularly to assist them to access treatment. [51]

DVA claims process

4.51 The committee heard about the difficulties experienced by some submitters trying to navigate the DVA claims process, and that some veterans and their families found it daunting or demoralising.[52] Some witnesses explained that they were assisted to submit their claims by an advocate but even with such assistance, veterans provided examples of the claims process taking up to 10 years.[53]

4.52 The committee heard that support is available to assist to navigate the claims process. For example, Ms Cosson, Secretary of DVA, told the committee:

> We're happy to sit down with a veteran and help them put forward what they are claiming. Certainly in the…consultation—that we had in Adelaide and we propose having around the country, where a veteran does present, which happened in Adelaide, we're able to sit down with them and help them through the claiming process.[54]

4.53 Professor Nick Saunders AO, Chairperson of the Repatriation Medical Authority (RMA), emphasised the importance of using an advocate to help navigate the system:

> …there are a lot of veterans who actually could establish a causal link between their service and their health today if they actually went through it in a systematic way with their advocate and looked at a range of statements and principles and a range of conditions that they might have. For example,

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50 *Submission 16.4*, p. 3.

51 Ms Cosson, *Committee Hansard*, 11 October 2018, p. 63.

52 See for example Mr Wayne Karakyriacos, *Committee Hansard*, 31 August 2018, p. 11.

53 Mr Michael Bush, *Proof Committee Hansard*, 5 November 2018, p. 15; Mr Brian Carlon, *Proof Committee Hansard*, 5 November 2018, p. 22.

54 Ms Cosson, *Committee Hansard*, 11 October 2018, p. 62.

> we have a statement of principle for post-traumatic stress disorder. Indeed, the people who are advocating for chronic brain injury being caused by mefloquine say that there is significant overlap in the symptoms and there's confusion in the system. Well, if one does have post-traumatic stress disorder, it almost certainly will be able to be related to the service, and it will be able then to related to access to appropriate treatment and compensation—although…access to treatment is less of an issue now [that the non-liability pathway has been established].[55]

Liability and non-liability pathways

4.54 As previously noted, veterans may access DVA-funded services through two pathways. DVA stressed to the committee that there is help available to veterans in need under the non-liability pathway which does not need to be connected to service-related activities:

> In relation to any treatment for anything that's part of the [Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition] DSM-5, which is anything to do with a mental health condition, which includes brain injury, our veterans are eligible for free treatment. There are two pathways to get treatment with the Department of Veterans' Affairs. The first is through that non-liability line, where you don't need to prove your condition is related to service, and we will get you straight into treatment.[56]

4.55 Mr Kruizinga was positive about the establishment of the non-liability pathway:

> In recent times, DVA have added a new strain of help that they call 'non-liability health care'. I believe this is a great step forward—it means that any soldier can then go and find help for their mental health—but I think that's a DVA umbrella trying to hide the issue that we are talking about today.[57]

4.56 Mrs Kruizinga described how this change made a difference to the circumstances of her husband and family:

> When he was admitted into psychiatric in February for a month, he was only on the white card at that stage. I had to fight tooth and nail to keep him there, and they were wanting us to pay the cost, which was quite exorbitant. I was going to have to pull him out, because there is no way we could afford that. I think a week into his stay, this non-liability kicked in, which was great…otherwise I would have had to pull him out.[58]

4.57 Alternatively, veterans can submit claims through the liability pathway. DVA assesses these claims to establish whether the condition was related to the claimant's service. Claims are also assessed against Statements of Principles (SOPs). These inform decisions regarding claims for compensation or liability for service injuries,

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55 *Committee Hansard*, 15 October 2018, p. 5.

56 Ms Cosson, *Committee Hansard*, 11 October 2018, p. 60.

57 *Proof Committee Hansard*, 5 November 2018, p. 8.

58 *Proof Committee Hansard*, 5 November 2018, p. 8.

diseases and death under the legislation relevant to DVA.[59] SOPs are set out by the RMA, which noted that SOPs 'state the factors which 'must' or 'must as a minimum exist if service is to be accepted as contributing to a particular kind of disease, injury or death'.[60] Professor Saunders emphasised that:

> If an exposure can be causally related to a disease or injury then it can become a factor within a statement of principles, but we do not make statements of principles relating to exposures to drugs, toxins or those sorts of things.[61]

4.58 DVA explained that when a veteran makes a liability claim in relation to the use of antimalarials, it is necessary for DVA to establish that:

- the claimant had a diagnosable condition answering the claim;
- the claimant had taken a relevant antimalarial medication;
- the relevant SOPs (if one has been determined by the RMA) includes a causal factor relating to the use of that medication;
- any other requirements set out in the SOP factor are met; and
- the use of the antimalarial medication was related to the person's service.[62]

Statements of Principles with factors relating to mefloquine or tafenoquine

4.59 DVA advised that the RMA has included mefloquine and tafenoquine, either by name or in more general terms, as a potential causal factor in the SOPs for a total of sixteen conditions: 16 for mefloquine and six for tafenoquine.[63] The RMA told the committee that they:

> …are confident that we have included mefloquine or tafenoquine in statements of principle for all diseases or injuries which could be linked to taking these drugs based upon sound medical scientific evidence that meets standard epidemiological criteria when examining things for causation.[64]

4.60 The RMA noted that 'the wording of the mefloquine- or tafenoquine-related factors in these SOPs requires a close temporal link between the taking of the drug and the onset of the condition…reflecting the well-accepted evidence that these agents can have acute neuropsychiatric effects'.[65] Ms Cosson suggested that if a trial

59 RMA, *Submission 4*, p. 4.

60 RMA, *Submission 4*, p. 4.

61 *Committee Hansard*, 15 October 2018, p. 1.

62 *Submission 2*, p. 7.

63 The list of relevant SOPs was provided in the RMA submission: RMA, *Submission 4*, Attachment 2. DVA, *Submission 2*, p. 7.

64 *Committee Hansard*, 15 October 2018, pp. 12.

65 RMA, *Submission 4*, p. 6.

participant reported an adverse event during the trial, DVA may be able to use Defence's records to assist with establishing this temporal link required by the SOPs.[66]

4.61 As noted in Chapter 2, Professor Saunders emphasised that the RMA takes a very generous view of evidence when they write the SOPs.[67] Therefore in his view the key for many veterans is getting assistance from an advocate for example to establish a causal link between their service and their current health conditions as:

> …when the department has conducted reviews in the past about claims that have been turned down or groups of claims being turned down for a particular injury, when one looks through the list, there are many other factors whereby those people could have legitimately claimed and got access to compensation through the standard route. So there is access to the system. The statements of principles cover 94 per cent of the claims that are made in the department, and there is a higher rate of success for claims based on a statement of principle than for those six or so per cent of claims that are made, really, not based on statements of principle but relying upon medical opinion, and the like. So the system is there for people to be able to gain access to the outcomes of the system and assessment.[68]

4.62 Acknowledging the chronic and complex symptoms being presented to the committee, Professor Saunders also raised the SOP concerning 'chronic multisymptom illness' determined in 2014:

> We have a statement of principle on an illness called chronic multisymptom illness. This arose out of an inquiry that we conducted in relation to Gulf War syndrome. Although this did not satisfy the Gulf War advocate group that was presenting to us, it became quite clear to us that there were a significant number of veterans who had quite debilitating symptoms that fitted into particular patterns of illness, but this wasn't related just to serving in the Gulf War. In fact, it was related more broadly to deployment into hazardous environments. So we wrote a statement of principle called 'Chronic multisymptom illness'. That statement of principle is available today for those people who were deployed to, say, East Timor, took antimalarial drugs and now have debilitating symptoms that are broad-ranging.[69]

Antimalarial-related claims

4.63 DVA 'has maintained a record of specific claims relating to antimalarial medications since September 2016'.[70] As of 30 July 2018, 42 veterans had lodged 53

66 *Committee Hansard*, 11 October 2018, p. 62.

67 *Committee Hansard*, 15 October 2018, p. 8.

68 *Committee Hansard*, 15 October 2018, p. 5.

69 Professor Saunders, *Committee Hansard*, 15 October 2018, p. 5. See Statement of Principles concerning chronic multisymptom illness No. 55 of 2014.

70 DVA, Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 1].

claims since reporting commenced.[71] As at 15 October 2018, DVA had received claims from 44 veterans from a total of 71 conditions 'that have been contended as relating the use of antimalarial medications'.[72] DVA detailed the outcome of the 71 conditions considered:

- 29 have been accepted either consistent with the original claim or as relating to a different SOP;
- 24 have been rejected as either not meeting the requirement of the SOP or there being no diagnosed condition as claimed;
- six have been withdrawn by the veteran; and
- 12 are in progress.[73]

4.64 The veterans who made these claims were deployed to a range of locations as follows: East Timor (30 veterans), South East Asia (four veterans), Australia-Pacific region (five veterans), Middle East (two veterans), Africa (one veteran) and two veterans from an unspecified location.[74] The following table shows which antimalarial medications were being attributed by the veteran as the cause of the condition being claimed, and the outcome of the claim.[75]

Table 2: Outcome of claimed condition by antimalarial medication

Condition	Chloroquine	Doxycycline	Mefloquine	Tafenoquine	Mefloquine/ Tafenoquine	Mefloquine/ Doxycycline/ Tafenoquine	Chloroquine/ Primaquine	Unspecified	Total
Accepted as claimed	0	3	0	0	0	0	0	0	**3**
Accepted under another SOP	1	1	18	5	1	0	0	0	**26**
Rejected	0	3	9	1	1	0	1	1	**16**
No diagnosable condition	0	1	5	0	2	0	0	0	**8**
Withdrawn by veteran	0	0	6	0	0	0	0	0	**6**
In progress	0	3	4	1	0	4	0	0	**12**
Total	1	11	42	7	4	4	1	1	**71**

Source: DVA, Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 6].

71 DVA noted that a single claim may represent one or more conditions per veteran, and a veteran may have more than one claim for the same condition to reflect they may have entitlements to test the same claim under multiple Acts. Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 1].

72 Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 1].

73 Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 3]. Note: the six withdrawn conditions relate to one veteran.

74 Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 2].

75 Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 6].

Further investigation of claims by DVA

4.65 At the hearing on 11 October 2018, Ms Cosson noted that DVA are 'looking at each individual client claim to understand what the claim was that they were seeking and to try and understand a little bit further about why they were not accepted'.[76]

Claims team

4.66 On notice, DVA provided information about the composition of the claims team:

> The dedicated Complex Case Team in the Melbourne office consists of seven delegates (three APS6 and four APS5) supported by an EL1 Assistant Director, a contracted medical advisor and two social workers. The team previously consisted of four delegates and was increased to seven delegates when combined with the Mefloquine Claims Team. The delegates in the team are experienced and have expertise across the *Veterans' Entitlements Act 1986*, the *Safety, Rehabilitation and Compensation (Defence-related Claims) Act 1988* and the *Military Rehabilitation and Compensation Act 2004*. Mefloquine or other anti-malarial drugs claims receive a higher level of priority and all calls relating to these claims are handled by the Complex Case Team.[77]

4.67 DVA further advised that of the seven delegates processing claims, five have been in the team for greater than 12 months. The team also processes claims relating to physical and sexual abuse in the ADF and 'given the nature of these claims delegates are rotated after about 12 months'.[78]

What assistance and support are veterans seeking?

4.68 Given the range of challenges highlighted by veterans and their families, the committee explored what other assistance and support is being sought in relation to their health. A range of suggestions were put forward throughout the inquiry including: acceptance that use of mefloquine and tafenoquine are the primary cause of the veterans' health issues, improved response times by Defence and DVA, information and support for families, a proactive outreach program and tailored treatment programs.

Acceptance of antimalarials as the cause of health issues

4.69 A number of witnesses called for the use of mefloquine and tafenoquine to be recognised as the sole or primary cause of the veterans' ill health. Mr Kruizinga distinguished this from the current situation:

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76 *Committee Hansard*, 11 October 2018, p. 61.

77 DVA, Response to questions on notice from 11 October 2018 public hearing (received 1 November 2018), [p. 7]. See also Ms Cosson, *Committee Hansard*, 11 October 2018, p. 62.

78 DVA, responses to questions taken on notice at a public hearing on 11 October 2018 (received 1 November 2018), p. 7.

> …although DVA have added mefloquine and tafenoquine as the basis for several SOPs, as a contributing factor, I do not believe yet that DVA have acknowledged that mefloquine can be a sole factor.[79]

4.70 The AQFVA submission similarly advocated:

> That an SOP be established for chemically acquired brain [injury], quinolone poisoning or similar, to facilitate claims and compensation for veterans and their families exposed to these drugs during ADF clinical trials or general military service.[80]

4.71 Lieutenant General John Caligari AO DSC (Rtd), a commanding officer during the tafenoquine prevention trial, also stated:

> In my view, there is sufficient evidence to acknowledge that mefloquine and tafenoquine are the cause of significant suffering among them. I believe much more can be done, and needs to be done, to help them…I would like to see four outcomes from this inquiry: acknowledgement that it is possible that mefloquine and tafenoquine have an adverse effect on the mental health of some service personnel and that the treatment may be different to the common treatments for PTSD; commencement of suitable research to understand how best to treat those who have experienced adverse effects from the use of mefloquine and tafenoquine; initiation of a program to identify every service person who has been prescribed mefloquine and/or tafenoquine and has been adversely affected by those drugs; and alerting the treating GPs and mental health practitioners of these individuals that these people need to be dealt with under a common protocol as directed by DVA and not automatically treated with PTSD.[81]

4.72 Dr Remington Nevin told the committee:

> [A] veteran can derive a significant amount of relief simply from learning that it's not all in their head; that they're actually sick from a disease with a name that doctors recognise. I don't think the amount of relief that comes from simply having their lifelong concerns finally validated can be understated. Many veterans have suffered with this problem for 25 years. To be finally told that what they suspected all along is true, that their government unintentionally or unwittingly poisoned them, can itself be deeply therapeutic.[82]

4.73 Associate Professor Jane Quinn provided her view

> …until that acknowledgement is there, it doesn't really matter what we put in place—that system is still going to ignore that it exists, and that's always going to be a problem.[83]

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79 *Proof Committee Hansard*, 5 November 2018, p. 8.

80 *Submission 16*, p. 6.

81 *Proof Committee Hansard*, 31 August 2018, p. 20. The tafenoquine prevention trial compared tafenoquine and mefloquine use in 1 RAR in Timor-Leste from October 2000 to April 2001.

82 *Committee Hansard*, 11 October 2018, p. 7.

83 *Proof Committee Hansard*, 5 November 2018, p. 46.

4.74 Some of the family members of veterans participating in the inquiry also highlighted their desire to see the antimalarials publicly recognised as the primary or sole cause of the ill health experienced by veterans. Mrs Susan Armstrong, the wife of veteran Mr Mark Armstrong, explained to the committee that while they were not interested in assigning blame or looking for financial compensation, they hoped the inquiry could provide:

> …acknowledgement and acceptance of the existence of the permanent adverse health effects of mefloquine; education of medical doctors and specialists so they understand the permanent adverse health effects that can arise; funding for long-term studies and research into methods or tests for detection of toxicity and how to treat to mitigate the adverse health effects; real and practical support for the veterans and their families; and legislation prohibiting the testing of drugs on ADF personnel.[84]

4.75 At the public hearing in Melbourne, Mrs Raelene King cautioned:

> I find that if this isn't acknowledged—that tafenoquine and mefloquine have caused this problem—this is not going to move forward. It needs to be acknowledged that this is the cause of our problem. Without acknowledgement, it's not going to move forward.[85]

Improving response times

4.76 The committee also heard the view that Defence and DVA should respond more quickly when contacted by concerned veterans. Mr Benjamin Whiley explained that he waited two months to receive information from ADFMIDI about the medication he had taken and then several months to get an appointment with a doctor and then another four months for the recommended brain injury rehabilitation program to be approved and commence. Mr Whiley was concerned about the impact this sort of timeframe can have on veterans' health.[86]

4.77 The need for a timely response to assist veterans was noted by Mr Kel Ryan, National President, Defence Force Welfare Association:

> I have quite a deal to do with DVA in another capacity, and I would agree that DVA is becoming a lot more responsive than it was 10 or 15 years ago. But the fact that we're only now addressing this very issue, 15 or 30 years after the event, means, to me, we have to become a lot more agile with the way we deal with these issues. I know enough about soldiers and soldiering to say that people present with issues, often, many years after they've left the service, and they present because of triggers that might not have occurred 20 or 30 years ago that have suddenly occurred. So somehow or other we need to get a more agile process to deal with these issues.[87]

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84 *Committee Hansard*, 30 August 2018, p. 15.

85 *Proof Committee Hansard*, 5 November 2018, p. 31.

86 *Committee Hansard*, 30 August 2018, pp. 32–33.

87 *Proof Committee Hansard*, 30 August 2018, p. 27.

4.78 As noted above, some claims, even with the assistance of an advocate, have taken up to 10 years to be finalised. Some individuals the committee spoke to were clearly in need of more immediate assistance.

Information and support for families

4.79 As has been raised in other inquiries undertaken by this committee, support from the partners and family members of veterans is very important. Several veterans who provided evidence to this inquiry did so alongside partners, parents and other support people. Similar to the experiences of the veterans themselves, family members reported difficulties accessing information about the ADF trials, veterans' health records and any support that may be available.

4.80 Mrs Naomi Kruizinga, wife of a veteran, outlined some challenges her family experienced when in crisis.

> I was completely overwhelmed. I had three children trying to make sense of what had happened and unable to give their dad a hug at night. I had to keep going, and I was the only bread winner. There was no assistance from DVA. They couldn't do anything. Except offer a one-time payment of 900 [dollars] to tide us through. We have had to get food vouchers from RSL and bravery trust to get us [by]. Hock personal belongings to help us through. Why is there no help from your government for this? I am not the only family who is going through this right now.[88]

4.81 In addition to providing counselling services, Mrs Kruizinga asked that more coordinated support be available for families:

> Especially for the children as well—they do give us counselling, but there needs to be sort of a team involved that will come out and help assess each family individually and try and find out what supports they need, whether it's financial assistance, other things as well. There's no-one out there like that. We have to make the calls. When you're so busy dealing with him in hospital—I don't have the time and I have three children whose needs I have to look after as well. Having that team come in and help me would be highly beneficial, just to take that load off.[89]

4.82 The role of ex-service organisations was also discussed. Mr and Mrs Kruizinga explained that their children had attended 'highly beneficial' support programs with Legacy and also accessed some services from the RSL. Mrs Kruzininga explained that because there is no coordination between ex-service organisations, as well as with DVA, family members must approach each service individually to find out what assistance is available.[90]

4.83 When describing her experience, Mrs Raelene King also advocated for more support for children to be available:

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88 *Submission 90,* p. 2.

89 *Proof Committee Hansard,* 5 November 2018, p. 4.

90 *Proof Committee Hansard,* 5 November 2018, p. 4.

> I would also perhaps like to see a quinoline support group for all children of affected trial participants to establish what the impact these psychological effects have had on them. My children are adolescents and adults now. Personally, seeing my husband go through this has affected me deeply in so many ways. So try to imagine seeing this through the eyes of my children.[91]

Proactive outreach program

4.84 Several submissions and witnesses advocated for a proactive outreach program to be initiated whereby all trial participants are contacted individually to inquire about their health and to check whether support or assistance is required.[92] For example, Mr Benjamin Fleming, a veteran who participated in the mefloquine prevention trial, was supportive of a broad outreach program because:

> …there are a lot of people out there who don't know they have got the issue….Defence and DVA, et cetera, have in their means the ability to contact every individual who has consumed these drugs. The first step is very much to reach out to them and help educate.[93]

4.85 He called for a program 'funded to speak with every Defence Force member who consumed these drugs—not just one that focuses on sufferers in Townsville'.[94] Also appearing at the public hearing in Brisbane, Mr Whiley agreed that an 'outreach program is vital' and that such a program 'needs to occur at a faster priority'.[95]

4.86 The AQFVA called for the establishment of a working group:

> …encompassing veterans advocates experienced in the effects of quinoline toxicity with appropriate, independent advisers sourced from the military mental health community, family services, occupational health practitioners, brain injury rehabilitation specialists, neurologists, psychologists, cognitive and behavioural experts and psychiatrists, to establish a recommended assessment and treatment program for those affected by mefloquine and tafenoquine during their military service.[96]

4.87 It further suggested that such a group 'be appropriately resourced to deliver a national outreach and rehabilitation program for quinoline veterans and families in Australia'.[97] The AQVFA submitted a proposal to then Minister for Veterans' Affairs, the Hon Dan Tehan and DVA in December 2016 to direct a pilot outreach, rehabilitation and research program for quinolone veterans and families.[98] The

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91 *Proof Committee Hansard*, 5 November 2018, p. 28.

92 See for example, Name withheld, *Submission 48*, p. 2; Mr Karakyriacos, *Committee Hansard*, 31 August 2018, p. 14.

93 *Committee Hansard*, 30 August 2018, p. 33.

94 *Committee Hansard*, 30 August 2018, p. 32.

95 *Committee Hansard*, 30 August 2018, p. 32.

96 *Submission 16*, pp. 54–55.

97 *Submission 16*, pp. 54–55.

98 See Mr Stuart McCarthy, *Submission 94*, pp. 6–7.

AQVFA's outreach program proposal was supported by other participants in the inquiry.[99] Mrs Kruizinga emphasised that a broad ranging outreach program would also be able to provide assistance for families and advise about other support services:

> This is where having this outreach program that can do the advocacy and the support and all that for the families is really beneficial, because it's just too overwhelming. I'm just so focused on the children and my husband that I just don't get the time to do that.[100]

4.88 Associate Professor Quinn told the committee that when responding to the proposal from the AQVFA, Minister Tehan did not support the proposal and noted that there are existing services available through DVA, or through Defence for serving members.[101]

4.89 Dr Remington Nevin noted that the American Quinism Foundation has recommended that all recent American veterans be screened for a history of symptomatic mefloquine exposure.[102]

Tailored treatment programs

4.90 The committee heard views from veterans that current treatment options are not sufficient to meet their health needs. Veterans reported that the difficulty in obtaining a definitive diagnosis covering the complexity of their health issues also makes it more difficult to access treatment.

4.91 Mr Kruizinga explained that the DVA process is one of exclusion or elimination to reach a diagnosis, which in his case, after numerous tests, has not been reached.[103]

4.92 The Defence Force Welfare Association also expressed concern about the effect of an incorrect diagnosis:

> The absence of effective diagnostic routines, referral protocols and dedicated rehabilitation programs is leading to very poor health care. Affected individuals are commonly wrongly diagnosed with posttraumatic stress disorder (PTSD) or other mental health disorders and subsequently subjected to treatments which fail to improve their condition and may inadvertently make it worse. The patient's neurological and psychological difficulties arise not from a functional brain problem as current treatment follows but from a structural change problem, drug mediated, that will require a different treatment approach. Here in lies the reason for these individual patient's failure to thrive. And for their on-going treatment.[104]

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99 Mrs Raelene King, *Proof Committee Hansard*, 5 November 2018, p. 28.

100 *Proof Committee Hansard*, 5 November 2018, p. 4.

101 *Proof Committee Hansard*, 5 November 2018, p. 42.

102 Quinism Foundation, *Submission 17*, p. 11.

103 *Proof Committee Hansard*, 5 November 2018, p. 8.

104 *Submission 95*, p. 2.

4.93 Associate Professor Quinn noted she has received reports from veterans that address a 'common theme':

> That certainly seems to be the common theme that runs through the experience of the people that I talk to. They have ease of access to psychiatry and they have ease of access to counselling, but if they ask for something that sits outside any of those particular domains then all of a sudden [their] SOP and their claim doesn't fit, and accessing that treatment becomes almost impossible.[105]

Treatment for neurocognitive issues

4.94 As outlined in Chapter 2, the AQVFA has argued that mefloquine has caused 'lasting or permanent brain damage, with chronic symptoms typically misdiagnosed as PTSD or other psychiatric disorders'.[106]

4.95 Dr Nevin indicated that in his view that treatment 'is a little premature to discuss'.[107] However, veterans who provided evidence to the inquiry supported the view that additional treatments needed to be available that address potential brain injury and other neurocognitive issues.[108]

4.96 Associate Professor Quinn explained that treatments for brain injuries acquired from taking antimalarials are not currently available:

> I think the treatments that are lacking at the moment are those that are applied to an actual brain injury as opposed to those that are applied to a psychiatric condition. In the vast majority of cases of people who have suffered long-term side effects from these drugs, what we see is the profile of, essentially, a brain injury.[109]

4.97 Furthermore, Associate Professor Quinn explained that in her view, should someone be incorrectly diagnosed with PTSD, they will be unresponsive to that treatment:

> What we see is that people who are treated for post-traumatic stress disorder without having that as an absolute formal diagnosis that is 100 per cent correct—when that post-traumatic stress disorder is present as an accumulation of symptoms caused by that underlying brain disorder, they're actually non-responsive to the treatments for PTSD, and that's extremely common in this group.[110]

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105 *Proof Committee Hansard*, 5 November 2018, p. 43.

106 *Submission 94*, p. 1. See also *Submission 16*, p. 42. *Submission 16.1*, p. 6; The Quinism Foundation, *Submission 17*, p. 5; Defence Force Welfare Association, *Submission 95*, p. 2.

107 *Committee Hansard*, 11 October 2018, p. 6.

108 See for example, Ms Anne-Maree Baker, *Proof Committee Hansard*, 5 November 2018, p. 31.

109 *Proof Committee Hansard*, 5 November 2018, p. 42.

110 *Proof Committee Hansard*, 5 November 2018, p. 42.

How can the concerns raised by veterans be addressed?

4.98 While acknowledging the actions already undertaken by Defence and DVA to date, the challenges and barriers reported by veterans demonstrate that these actions are not meeting the needs of all veterans. The committee heard a number of suggestions from veterans about the assistance and support they would like. Noting the challenges of coming to an agreed position on the cause/s of their symptoms between the veterans and their advocates and the medical community, the committee discussed how best to address their health concerns.

Improving connections with the veteran community

4.99 The committee heard various suggestions for how to improve the connections between veterans and service providers, to ensure that veterans are accessing the support to which they are entitled. It appeared that while submitters agreed on this general point, views varied on how this could be achieved. While many in the veteran community were calling for a proactive outreach program, other evidence to the inquiry highlighted concerns with that approach.

Ethical and practical concerns regarding proactive outreach

4.100 The committee was told that this kind of 'active outreach program' could cause additional and unnecessary suffering to veterans and 'could also undermine measures being applied more broadly to address the mental health of veterans'.[111] Associate Professor Harin Karunajeewa cautioned that it is:

> …hard to see how such a program could be implemented without implicitly suggesting to recipients of the outreach that their symptoms are indeed related to previous drug exposure. This approach is therefore highly susceptible to an important and very well characterised phenomenon known as 'recall bias'. It effectively becomes a 'self-fulfilling prophecy' and one which I believe would contribute significantly to anxiety and other psychological morbidity in these veterans.[112]

4.101 Defence has on a number of occasions indicated it does not support undertaking a proactive outreach program as it is concerned that this approach could potentially cause veterans undue harm. VADM David Johnston AO, Vice Chief of the Defence Force explained:

> Defence has considered whether individual follow-up of all those who were involved in the antimalarial studies in the late nineties and early 2000s is warranted. The vast majority of individuals who have taken these medications are unlikely to have ongoing health problems. Our view has been that contacting this majority might cause more harm than good. It may cause unnecessary worry to individuals who have no reason to be concerned. The significant profile of this issue now and the confusion that

111 Associate Professor Harin Karunajeewa, *Submission 15*, [pp. 10–11].

112 *Submission 15*, [pp. 10–11].

> may now exist amongst study participants mean that we need to keep this approach under review.[113]

4.102 Defence suggested that there may be benefit in future outreach activities being:

> …focused more broadly on encouraging all veterans with any health concerns to seek help, rather than specifically focussing on this group. It remains pivotal that veterans and their families understand the services available to them regardless of their diagnosis, many of which can be accessed through DVA or through their GP, who are best placed to investigate, manage and if necessary refer patients for specialist advice.[114]

New consultation program

4.103 An important issue is enhancing trust with this group of veterans as the committee heard some have lost trust in the system, such as Ms Anne-Maree Baker, who told the committee 'I have a real distrust in the government, the military and any institutions because of my experiences since 2001 when my health started to decline'.[115] Mr Stuart McCarthy similarly said 'I have zero trust and zero faith in any democratic institution in this country, because the culture of those institutions is denial, at best'.[116]

4.104 As outlined above, DVA will be holding a series of consultation forums. The consultation forum mechanisms may present an opportunity to enhance trust by facilitating greater collaboration and fostering connections between veterans, families, advocates and service providers, particularly DVA.

Improving cooperation

4.105 Ms Cosson, Secretary of DVA, acknowledged that there has been differing views on what should be regarded as 'outreach' and, as a result, DVA is undertaking what they are referring to as 'consultation'.[117] Ms Cosson observed that, among the attendees at the recent Adelaide consultation forum, there was not a strong level of awareness about what services are available generally to veterans:

> Recently we had a consultation session in Adelaide and we talked with our veteran community. Forty of our veterans and families participated in that consultation. What seemed to be a gap in understanding is that when we introduced non-liability health care in the budget last year we extended that free treatment for any condition that's listed in the DSM-5.[118]

113 *Committee Hansard*, 11 October 2018, p. 46.

114 *Submission 1*, pp. 31–32.

115 *Proof Committee Hansard*, 5 November 2018, p. 28.

116 *Committee Hansard*, 30 August 2018, p. 8.

117 *Committee Hansard*, 11 October 2018, p. 64.

118 *Committee Hansard*, 11 October 2018, p. 60.

4.106 Following the 11 October 2018 public hearing, DVA provided more detail about the Adelaide forum including a summary of areas discussed which included: health experiences related to ADF service (including experience with antimalarial medicines), a lack of awareness of what supports are available through DVA or Defence and concerns about how to access the mental health workforce eg. psychiatrists and psychologists in Adelaide and South Australia.[119]

4.107 A number of suggestions came out of the public forum held in Adelaide. DVA advised that attendees were invited to provide feedback via a short survey and that overall, attendees reported that the 'forum provided helpful information and a good opportunity to openly discuss their concerns'. However:

> …some felt that the discussion became too emotional and that a smaller group might help facilitate a more focused and comfortable discussion for attendees. Attendees also identified that additional information on available supports and services, including non-liability health care arrangements, would be helpful.[120]

4.108 Regarding the forum in Adelaide, Associate Professor Quinn noted the need to build on the information provided:

> The other thing that did seem to be a deficit in the way the first one [session in Adelaide] was carried out was that there really wasn't any provision of information about what the next step for those people needed to be other than 'put in your claims'. So we always give effect to this circular—whatever you want to do, put in your claims.[121]

4.109 Associate Professor Quinn also suggested that DVA could proactively contact groups such as the AQVFA to inform them of upcoming consultation or information-sharing activities. She noted that in relation to the DVA sessions held in Adelaide:

> …what was interesting was that we [the AQVFA] weren't informed of any of them directly. We found about the dates of all of them through ex-service organisation members who have been on the mailing lists for them, which is odd because I have Liz Cossin's personal email address and Tracy Smart's mobile number and either of them could have given me a call and told me when they were.[122]

Ensuring GPs have access to relevant information

4.110 One of the key messages from Defence has been for those concerned to seek assistance from medical practitioners. GPs are therefore central to ensuring veterans have access to a range of health services and ongoing support. Dr Penny Burns,

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119 DVA, responses to questions taken on notice at a public hearing on 11 October 2018 (received 1 November 2018), [p. 9].

120 DVA, responses to questions taken on notice at a public hearing on 11 October 2018 (received 1 November 2018), [p. 10].

121 *Proof Committee Hansard*, 5 November 2018, p. 44.

122 *Proof Committee Hansard*, 5 November 2018, p. 44.

representing the Royal Australian College of General Practitioners (RACGP) explained the organisation's role:

> The role of the RACGP in this discussion is around ensuring general practitioners are available to provide ongoing support to veterans affected by mental health symptoms and/or physical symptoms, whatever the cause. Their aim is to continue to update GPs so they can provide the best evidence based treatment on an ongoing basis. The aim is to decrease the level of dysfunction experienced with symptoms and get people back to more normal lives. In practice, when people present with symptoms—mental health issues, for example—it's sometimes not possible to definitely define a cause, but, in most cases, we're still able to look at managing symptoms to improve the conditions.[123]

4.111 Furthermore, Dr Burns emphasised:

> In summary: the RACGP is keen to ensure easy access by veterans to GPs for any support needed—be it for mental health symptoms and/or physical symptoms, or just general distress; whatever the cause—and to ensure that GPs are educated to provide the best possible evidence based support, diagnosis and treatment for veterans.[124]

4.112 Evidence to the inquiry has reported varying levels of awareness among GPs of the mefloquine and tafenoquine antimalarial drugs and it was suggested that more needs to be done to better educate GPs about the issues being reported by veterans.[125]

4.113 Officials from DVA recognised the important role of GPs to provide assistance to veterans as well as the role that DVA has to support and educate GPs:

> …What we are very aware of, as I've looked into this and I've worked with my colleagues and I've worked across the last year, is that we need to find ways to educate our GPs better so that, when veterans present with this type of disorder, there is a very clear, signposted way for people to get to these specialists—because it is a specialist area.[126]

4.114 Dr Burns said most GPs would have a reasonable understanding of mefloquine due to the fact that mefloquine 'has been used for quite some time'. She spoke about the resources that have been made available to increase awareness about mefloquine:

> My understanding of most of the GPs who I know is that they would have a reasonable understanding of that. There have also been clinical guidelines brought out by the Joint Health Command. Recently, I think that the Gallipoli Medical Research Foundation and the Returned Services League of Australia put out a comprehensive brief on some PTSD stuff. And there

123 *Committee Hansard*, 11 October 2018, p. 15.

124 *Committee Hansard*, 11 October 2018, p. 15.

125 See for example, Mr Benjamin Fleming, *Committee Hansard*, 30 August 2018, p. 33.

126 Dr Hodson, *Committee Hansard*, 11 October 2018, p. 65.

> has also been some stuff coming out recently about mefloquine as well. So there's a lot of education that comes out continually to GPs around that.[127]

4.115 Dr Burns noted that as tafenoquine is new, GPs would not typically have received information about that yet:

> Tafenoquine, no. I hadn't actually heard of it before or seen it before the invitation to this inquiry. So, if I'm an example of the average GP, I would presume that they don't have much information around that.[128]

4.116 Mr Karl Herz, Biocelect, informed the committee about the information they will be providing to GPs leading up to the official release of tafenoquine. As well as the information that is already provided on the TGA website, Biolcelect is finalising a 'Dear Doctor' letter which will provide information about the medication with a focus on explaining the contraindications.[129]

Ensuring information sharing between health professionals and DVA

4.117 As noted earlier in the chapter, DVA has undertaken activities to increase GPs' awareness of the use of antimalarials in the context of the veterans' community. Dr Burns noted that the clinical guidelines for GPs produced by DVA and Defence 'are fantastic' and the importance of ongoing information sharing and promotion across GP groups:

> I think that one of the things that need to happen is that it needs to be promoted through all the GP groups continually, and workshops and webinars are the ways that GPs are now accessing information. I think having the GP groups involved—so the AMA [Australian Medical Association], the college, ACRRM [Australia College of Rural and Remote Medicine], the various groups, promoting it. I think webinars, workshops, guidelines particularly—GPs love guidelines and workshops. At the moment, there's a big conference, the annual GP conference, GP18. That's another way of getting information out to GPs.[130]

4.118 Dr Burns suggested that the provision and promotion of this sort of information was particularly relevant around major bases as well as in other locations where there is high volume of 'travel back and forth between malarial areas'.[131]

4.119 On notice, the RACGP explained that a RACGP representative attends the DVA Health Providers Partnership Forum[132] meetings three or four times a year to provide advice to DVA about developing information resources for veterans. Attendance at these meetings also facilitates information sharing back to the RACGP about DVA programs. Furthermore, the RACGP 'helps to distribute DVA information

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127 *Committee Hansard*, 11 October 2018, p. 16.

128 *Committee Hansard*, 11 October 2018, p. 16.

129 *Proof Committee Hansard*, 8 November 2018, p. 22.

130 *Committee Hansard*, 11 October 2018, p. 16.

131 *Committee Hansard*, 11 October 2018, p. 16.

132 See DVA, *Health Providers Partnership Forum, Terms of Reference*, p. 1.

and resources through RACGP publications' and has endorsed a number of resources that provide information and support for veterans.[133]

Additional research underway

4.120 Professor Sandy McFarlane AO, Director of the Centre for Traumatic Stress Studies, stressed the need for research which is independent in order to provide reassurance to veterans about the findings.[134] The committee is aware that Defence and DVA have jointly commissioned the University of Queensland to undertake a research study on 'Self-reported health of ADF personnel after use of antimalarial drugs on deployment'[135] using 'de-identified data extracts from the Bougainville, Timor-Leste, and Solomon Islands deployment health studies'.[136]

4.121 In its submission, DVA explained the new research will:

> …focus specifically on the health outcomes of deployed veterans who took anti-malarial medications. It is anticipated that this research will be completed in the second half of 2018.[137]

4.122 Defence added that this research will examine the following research questions:

> a. Did deployed veterans who reported taking mefloquine have different rates of mental and general health outcomes compared to veterans who reported taking doxycycline or other antimalarials?
>
> b. Did deployed veterans who reported taking primaquine on return to Australia have different rates of mental and general health outcomes compared to veterans who did not?
>
> c. Did deployed veterans report a significant reaction to specific medications received during their deployment or raise use of antimalarial drugs as an area of concern in response to open ended questions?[138]

4.123 At the time of the hearing in October 2018, there was no further information available about the ongoing research. It was confirmed that the research will be finalised later in 2018 and that the report will be published.[139]

The need for a multi-disciplinary approach

4.124 The health issues identified by veterans in this inquiry are complex with several individuals submitting long lists of symptoms and documenting a range of

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133 RACGP, responses to questions taken on notice from a public hearing on 11 October 2018 (received 31 October 2018).

134 *Submission 58,* p. 4.

135 Department of Defence, *Submission 1*, p. 42.

136 Department of Defence, *Submission 1*, p. 42; DVA, *Submission 2*, p. 6.

137 *Submission 2*, p. 7.

138 Department of Defence, *Submission 1*, p. 42.

139 Ms Veronica Hancock, Acting First Assistant Secretary, Veterans' Services Design, *Committee Hansard,* 11 October 2018, p. 68.

conditions. Some had been diagnosed with particular conditions by a health professional while others were still undergoing various tests and consults to determine a diagnosis.

4.125 It was noted that responding to such varied and complex health needs requires a multi-disciplinary approach. One veteran described the range of supports he needs as follows:

> One of my recommendations moving forward is that sitting in front of a psychiatrist and being prescribed medication is not going to help or do anything for my brain injury. What I need is psychosocial support…I've got to the point where I need to start re-learning how to do things. I've managed to get access to a social worker and I'm basically learning how to schedule a day and tasks—things like that—and that's the support that we need.[140]

4.126 The RACGP has defined 'multidisciplinary care' as occurring:

> …when professionals from a range of disciplines with different but complementary skills, knowledge and experience work together to deliver comprehensive healthcare aimed at providing the best possible outcome for the physical and psychosocial needs of a patient and their carers'.[141]

4.127 Health professionals may include community health professionals, general practitioners, and medical specialists. This approach is often used to treat and support people with conditions such as cancer, and systematic approaches to team based care are also emerging in 'primary care clinical areas such as diabetes, aged care, mental health and disability'.[142]

4.128 Associate Professor Quinn emphasised the importance of including a broad support network when providing treatment:

> Managing those [people with brain injuries] isn't just a matter of giving somebody a script with an antipsychotic or a sedative drug and expecting them to go away and get better. There is also a whole family support network that needs to be drawn up around somebody with a long-term brain injury. If we were looking at somebody who had been brain injured in a car accident and was going to be anticipated to have long-term neurological and cognitive deficits, there's no way that we would be suggesting that that person was going to manage their environment, manage their work-life balance or manage their employment prospects without having a network of support around them and their family. This is the thing that is missing when we have a situation with a system that doesn't recognise this as a brain injury.[143]

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140 Mr Whiley, *Committee Hansard,* 30 August 2018, p. 35.

141 RACGP, *The RACGP Curriculum for Australian General Practice 2011*, p. 453. See also GK Mitchell, JJ Tieman and TM Shelby-James, 'Multidisciplinary care planning and teamwork in primary care', *Medical Journal of Australia*, 2008, vol. 188, no. 8, S61–4.

142 RACGP, *The RACGP Curriculum for Australian General Practice 2011*, p. 454.

143 *Proof Committee Hansard,* 5 November 2018, p. 42.

4.129 Dr Stephanie Hodson CSC, National Manager, VVCS, DVA, acknowledged that it can be challenging to confirm a diagnosis when individuals present with a range of complex symptoms. The symptoms reported by veterans are wide ranging: concerns about the 'neurocognitive element', anxiety, PTSD as well as other 'somatic symptoms' including digestive issues and skins problems. She acknowledged that the complexity of these issues requires a holistic response:

> All of this means that we've got to get to person-centred care. We've got to have a way that we assess comprehensively the individual for all those domains and then assist them to get to pathways. Just saying, 'Go to your local GP,' doesn't necessarily mean that you're going to get the sort of wraparound assessment you need. We need to help GPs actually identify the more complex individuals who we need to put into a signposted pathway where we can link them to the right professionals.[144]

4.130 Dr Hodson spoke further about the recognition by DVA that some individuals need tailored, wrap around assistance which needs to include neurocognitive aspects:

> Across this journey, we've reached back into the department. We hadn't, when we first started, thought a lot about rehab. With the pathways to care that [Mr Stuart McCarthy] talked about, we are now figuring out how someone gets there from maybe turning up in a VVCS office. We do the right assessment and say, 'We do think there are some problems here that are not down the anxiety end of the spectrum, or PTSD; they're actually in the neurocognitive end,' and we now need to get those people to rehab specialists, to speech pathology, and we are working for the first time ever with rehab occupational therapists. There's a whole specialty here.[145]

Neurocognitive Health Program

4.131 In addition to offering existing treatments and support through DVA's non-liability pathway, DVA advised that they are developing a new Neurocognitive Health Program to assist veterans who may indicate symptoms of a neurocognitive disorder (NCD). This program has been developed following feedback from veterans that they have been unable to access appropriate support to address some of the concerns they have attributed to mefloquine use.

4.132 Dr Hodson advised that:

> The DSM-5 [Diagnostic and Statistical Manual of Mental Disorders] made quite a big step forward around the fact that we all do tend to forget the brain and psychology. Mental health is all interconnected, and it starts with the brain. There is an area in the whole diagnostic continuum which is about neurocognitive disorders, which can be caused from a range of issues. It can be exposures, it can be playing sport, it can be mild traumatic brain injury and it can be long-term life alcohol use. All of these can result in

144 *Committee Hansard*, 11 October 2018, p. 66.

145 *Committee Hansard*, 11 October 2018, p. 65.

> impacts that are about a loss in memory, speech, neurocognitive functioning.[146]

4.133 Dr Hodson explained that a number of veterans from the 'mefloquine cohort' had raised concerns that when they have tried to access DVA services to discuss a possible brain injury, the response was to discuss PTSD.[147] This experience reported by Dr Hodson is consistent with the evidence to the committee's inquiry.

4.134 Dr Hodson explained that DVA had reflected on those representations and acknowledged that the response to veterans' concerns may need to change:

> We acknowledged, about a year ago, that we were not well equipped to be able to do those assessments. It's actually a very specialised area within the community. Over the last 12 months, we've been working really hard to look at whether this is an area we can measure. The good news is that we've we talked to Westmead Hospital and we've talked to people like Professor Richard Bryant and Dr Ian Baguley, who do specialist work in this area, and they've said that the science has really moved forward. A lot of it has come out of the US to do with mild traumatic brain injuries. In fact, we've now got much better neurocognitive screening that we can do. Importantly, there is remediation we can do to bring about better outcomes.
>
> What we're trying to do at the moment is develop a pathway so that, if you come in, we can baseline where your functioning is. For anyone who has served in the military, that's super important. If you've had a 20-year career, you may have been around exploding ordnance, you may have played a lot of rugby, you have potentially had toxic exposures, you may have drunk a bit of alcohol—there are a whole range of reasons why your cognitive functioning would be putting you at risk for early onset Alzheimer's down the track. We want to be able to assess functioning baseline for anyone who is worried about functioning. Where we find there is a problem, we have to have pathways to care.[148]

4.135 It is envisaged that the program will be accessible to veterans assessed as requiring treatment from anywhere in Australia. The assessment of current functioning and provision of treatment will not be linked to any possible cause.[149]

4.136 Dr Hodson further reported to the committee advice she has received from a neuroscientist:

> …it doesn't really matter whether the inflammation in the brain was caused by PTSD or it came from a toxic exposure; at the end of the day we've got to work with the inflammation of the brain.'[150]

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146 *Committee Hansard*, 11 October 2018, p. 65.

147 *Committee Hansard*, 11 October 2018, p. 65.

148 *Committee Hansard*, 11 October 2018, p. 65.

149 *Submission 2*, p. 6.

150 *Committee Hansard*, 11 October 2018, p. 65.

4.137 This program is being developed 'initially through a Discovery Phase of consultation and co-design to establish what the service would need to provide'.[151] In his submission, Professor McFarlane, noted that he has been asked by DVA to advise on the development of the Neurocognitive Health Program. Mr Stuart McCarthy also advised the committee that the AQVFA was invited to 'co-design this program with them, in consultation with ABI rehabilitation specialists already experienced in providing health care to affected veterans…'.[152]

4.138 Associate Professor Quinn also discussed the development of the Neurocognitive Heath Program and in particular focused on the benefits of the co-design model being used for its development as an example of different groups working together in a cooperative manner:

> I think we're beginning to work on that with the neurocognitive health program that's being extended through VVCS, now Open Arms, with DVA presumably sitting in the background of that. So that program encompasses us, as QVFA, and senior leaders from Open Arms/VVCS. In that process, we have engaged a number of healthcare experts who sit outside the normal VVCS psychological counselling banner. Those include people who are specialist in brain rehabilitation, people who are specialist in trauma psychiatry, people who are specialist in providing family support, particularly around rehabilitation. That's the kind of team that you start to need to build together. It doesn't exist currently under the DVA/VVCS banner. So these are specialists and agencies that are not routinely employed by either of those organisations. But they are the types of agencies, and we'll find out who those people are, and that group will extend the more that we go through that process.[153]

4.139 The committee notes that DVA has discussed the development of the Neurocognitive Health Program at the recent consultation forums and will continue to inform veterans about the program.

151 *Submission 2*, p. 6.

152 Mr Stuart McCarthy, *Committee Hansard*, 30 August 2018, p. 2.

153 *Proof Committee Hansard*, 5 November 2018, p. 46.