

# Chapter 5

## Conclusions and Recommendations

### Medical concerns

5.1 The inquiry focused on three issues raised which will be addressed in turn. First, the claims that the current symptoms experienced by individuals are due to taking mefloquine and/or tafenoquine over 18 years ago. The committee spoke with the individuals and groups making these claims and then with the medical community in Australia, particularly those organisations responsible for assessing these claims.

5.2 As in the executive summary, the committee again states that it is not comprised of medical experts and so can make no medical findings or rulings on this matter but it facilitated the case from each side to be presented. It is clear to the committee that in the view of the medical professionals, the weight of medical evidence does not support the claim that their current symptoms are caused by antimalarial use 18 years ago. More specifically, in summary, the committee was told that long term problems as a result of taking mefloquine are rare and there is no compelling evidence that tafenoquine causes long term effects.

5.3 It is important to note that although individuals presenting evidence to the committee often did not clearly distinguish between them, mefloquine and tafenoquine are different drugs that act differently in the body.

5.4 In relation to mefloquine, the committee notes that there has always been recognition by Defence that mefloquine, like any drug, has side effects and this has been taken into consideration in the development of health policy. The committee accepts that Defence, when deploying ADF personnel to malarious areas, takes it duty of care seriously<sup>1</sup> and needs to provide the best protection for them for field conditions and to have more than one option available in case the first line antimalarial, doxycycline, is not tolerated or the deployment is to an area with antimalarial resistance.

5.5 The medical evidence provided to the committee shows that the incidence of long term or persistent neuropsychiatric adverse reactions to mefloquine is very rare. The committee heard there have been an estimated 40 million doses of mefloquine worldwide, with safety data on at least 1 million people in a recent published Cochrane review. The committee was provided with no evidence that the same symptoms reported by some veterans are manifesting in the Australian population or across the world in the civilian population.<sup>2</sup> The committee heard that there is no evidence of an emerging global public health issue.

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1 Vice Admiral David Johnston AO, Vice Chief of the Defence Force, Department of Defence, *Committee Hansard*, 11 October 2018, p. 45.

2 For example, primaquine has been used for more than 60 years in the USA and Australia. See 60P, *Submission 9*, p. 2.

5.6 While sympathising with the veterans who spoke with the committee and hoping for them to get the help they need, the medical experts have been very clear with the committee that the medical evidence does not support their contention that their current health conditions are caused by the drugs they took over 18 years ago.

5.7 Mefloquine was an approved drug at the time of the trials, tafenoquine was not. The committee notes that the newer drug tafenoquine has undergone rigorous safety evaluation by the US FDA and the Australian TGA. TGA's Advisory Committee on Medicines and the US FDA's Antimicrobial Drug Advisory Committee (AMDAC) have all had input for both indications, prevention and radical cure, and the findings are consistent. The processes of the US FDA and TGA included an audit of the relevant Defence studies which would have affected registration if anomalies or concerns about clinical practice had been found. On the contrary, the committee was told that the auditor found that the level of oversight of the studies was of a very high standard. The committee also notes that for the independent regulators, commercial concerns of pharmaceutical companies are not part of their considerations.

5.8 The committee is reassured that every effort has been made by the systems and regulators in place to ensure the safety of patients who have access to mefloquine and who will have access to tafenoquine. The committee was also reassured by the efforts of the pharmaceutical companies to address the concerns being raised by investigation and transparency of data. The committee wishes to note that it received full cooperation during the inquiry by the pharmaceutical companies who provided submissions, supplementary submissions to address specific evidence and appeared at a hearing, with some witnesses travelling from overseas to provide evidence in person.

5.9 The committee has confidence that Australia's independent medical bodies have looked specifically at the issue of acquired brain injury (ABI) from the use of mefloquine or tafenoquine. The committee was informed that the claim that taking mefloquine and tafenoquine results in ABI is not backed by definitive evidence. In August 2017, the Repatriation Medical Authority (RMA) found there was insufficient sound medical evidence to support this claim. This decision was reviewed by the Specialist Medication Review Council which in September 2018 supported the decision of the RMA.

5.10 The committee was reassured that, should any sound medical-scientific evidence pertinent to this inquiry arise in the future, it would be identified through existing channels and responded to by Defence and DVA. Existing monitoring mechanisms include the regular reviews of the evidence undertaken by the RMA and the work undertaken by Defence Joint Health Command (JHC).

5.11 It was suggested to the committee that it was hearing mostly from malariologists.<sup>3</sup> This is not the case as can be seen by the range of evidence detailed in Chapter 2. The wide range of specialists contributing to accumulating and analysing medical data was evident to the committee. The committee notes that the US FDA engaged specialists including not only malariologists but psychiatrists,

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3 Dr Nevin, *Committee Hansard*, 11 October 2018, p. 7.

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epidemiologists, postmarketing surveillance professionals and others. The TGA has toxicologists, pharmaceutical chemists, inspectors for the manufacturing facilities as well as the ability to call on external advice from an advisory committee of doctors, community representatives, epidemiologists and statisticians. The committee notes the range of professionals who reviewed the information in the RMA and SMRC with specialists drawn from pharmacology, neurology, mental health, neuropsychology as well as medical academics and epidemiological academics.

5.12 In conclusion, on this aspect, the committee respects the medical findings of the various regulators and their experts as well as the vast amount of evidence from international and domestic studies and clinical experience. Also, this issue seems to be manifested in military populations where it appears to the committee that trying to assign a single cause to veterans' illnesses does not reflect the many potential contributors to their physical and mental health at the time and in the many years since the medications were taken.

5.13 The committee notes that the concerns of veterans have not been ignored by pharmaceutical companies or regulators. Adverse events reported more recently for tafenoquine were followed up, scrutinised and this work included in the information provided to the US FDA and TGA. Dr Nevin presented to the US FDA. The committee notes that he was the only person who submitted evidence critical of the proposal to approve tafenoquine. The committee is reassured that the medical concerns raised with the committee have been taken into consideration by the independent regulators which have recently approved tafenoquine and whose job it is to focus on safety and efficacy of medications.

5.14 However, the committee does not doubt that the symptoms being experienced by individuals are real and regardless of the cause or causes, these veterans are unwell and should receive the assistance to which they are entitled. It has therefore been the focus of the committee to ensure that any current and past ADF members receive appropriate treatment and the support they need. The committee notes that this is not a different view to that stressed by Defence and DVA, ie. that regardless of the cause of the symptoms, help is available.

5.15 The committee understands that the individuals and families who spoke with the committee are searching for answers to their poor health and acknowledges the comfort and support felt by most veterans and family members who are part of the group organised by the AQVFA. The committee is, however, concerned that this support does not come at the expense of them reaching out to receive available assistance because it does not come under the label they would prefer it to have. The committee is also concerned that the efforts of such advocates may unnecessarily cause public concern and negatively affect the global effort to eradicate malaria.

5.16 The committee was concerned at the personal nature of some submissions and evidence from advocates questioning the honesty and motives of witnesses with whom they disagree. The committee accepts that officials and other witnesses have provided evidence to the committee in their professional capacities in good faith. In these cases the committee facilitated an exchange of views and the individuals mentioned were given the opportunity to respond to the submissions and evidence.

## **ADF participation in medical research**

5.17 The second issue raised with the committee was the conduct of the trials. The issue of ADF members participating in medical research is complex. The committee is concerned that some members may not fully engage with the information provided by researchers if they perceive participation in the research to be a mandatory or routine part of their role. The committee also believes that members are potentially vulnerable to feeling pressured to participate by their superior officers due to the hierarchical culture of the military.

5.18 However, the committee does not believe that all medical research with members of the ADF should be prohibited, provided it does not disrupt the work of the ADF and has been approved in accordance with the National Statement on Ethical Conduct in Human Research (National Statement). This is because research is essential for advancing medical care and force protection measures, and the ADF has a duty of care to protect and maintain the health of its personnel.

### ***Informed consent during the trials***

5.19 As noted above, the processes of the US FDA and TGA included an audit of the trials involving tafenoquine, which Defence characterised as representing 'a thorough, independent validation of all aspects of the conduct of the studies'.<sup>4</sup> Moreover, allegations of misconduct in some of the trials involving the use of mefloquine and tafenoquine have been investigated by the Inspector-General of the Australian Defence Force (IGADF), a statutory role that is independent of the ordinary chain of command. The IGADF found that the trials undertaken by the Australian Malaria Institute from 2000 to 2002 in East Timor involving mefloquine and tafenoquine 'were conducted ethically and lawfully' in accordance with the guidelines issued by the National Health and Medical Research Council (NHMRC) and the Therapeutic Goods Administration.<sup>5</sup> It also concluded that members voluntarily consented to participate in the trials involving mefloquine and tafenoquine, and were informed of the potential side effects known at the time.

5.20 Some submitters have not accepted the findings of the audit and investigation and have called for a Royal Commission. However, the committee has not received evidence that undermines the existing independent findings, and so does not support a further investigation. The committee was concerned to hear that some ADF members who agreed to participate in the trials felt that they were not provided sufficient information, or were pressured into participating. The committee recognises that this perception is distressing for some veterans and their families. Therefore, the committee makes some recommendations for improving the consent process.

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4 Defence, *Supplementary submission 1.1*, p. 5.

5 IGADF, *Inquiry report into issues concerning anti-malarial trials of the drug mefloquine between 2000 and 2002 involving Australian Defence members deploying to East Timor*, 2016, pp. ii–iii.

### ***Improving the process of providing informed consent***

5.21 The committee believes that issues of informed consent should be carefully considered when study protocols are developed by researchers, and when the current Departments of Defence and Veterans' Affairs Human Research Ethics Committee (DDVA HREC) reviews and decides whether or not to approve the research. This is in accordance with the NHMRC National Statement and the recent recommendations made by the IGADF.

5.22 The committee notes that the DDVA HREC is comprised of a range of members, including a veteran, lawyer, lay people, a pastoral care member, a civilian clinical care provider and others with relevant experience in research.<sup>6</sup> The DDVA HREC terms of reference also establish that 'at least one third of the members are to be external to Defence and DVA'.<sup>7</sup> The committee views these requirements to sufficiently ensure a range of perspectives are represented during the consideration of new study protocols.

5.23 The committee was pleased to note Air Vice-Marshal Smart's letter requesting DDVA HREC also consider new methods of ensuring the military chain of command does not influence the voluntary choice of members of the ADF to participate or not in research.<sup>8</sup> The committee encourages DDVA HREC, Defence and the Department of Veterans' Affairs to implement measures to achieve this aim. It is supportive of initiatives including providing a standard script to Command and standard briefing materials to prospective participants, and engaging an external agency observer to monitor, evaluate and report on the consent process.

5.24 Defence informed the committee that DDVA HREC already considers the issue of informed consent in military populations each time it considers a research proposal 'to ensure that there is no coercion, real or perceived, in the recruitment of participants from the ADF'.<sup>9</sup> This responsibility is implicitly contained in the DDVA HREC terms of reference as it reviews research protocols in accordance with the National Statement, which covers issues of informed consent.<sup>10</sup> However, the committee view is that there is an opportunity to develop the DDVA HREC terms of reference to explicitly note its responsibility to consider the vulnerability of prospective participants to coercion.

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6 Defence, *Submission 1.1*, p. 15.

7 Defence and Department of Veterans' Affairs, *The DDVA HREC Terms of Reference*, pp. 2–4, <http://www.defence.gov.au/health/hrec/> (accessed 11 October 2018).

8 Defence, *Letter form AVM Tracy Smart Am to Mr Ian Tindall*, Chair DDVA HREC, 4 October 2018, [p. 1] (tabled 11 October 2018).

9 Defence, *Submission 1*, p. 33.

10 *The DDVA HREC Terms of Reference*, p. 1; NHMRC, Australian Research Council and Universities Australia, *National Statement on Ethical Conduct in Human Research*, p. 68.

## **Recommendation 1**

**5.25 The committee recommends that the terms of reference of the Departments of Defence and Veterans' Affairs Human Research Ethics Committee be updated to explicitly include consideration that prospective research participants may be vulnerable to perceived coercion to participate.**

5.26 Once DDVA HREC has approved a study protocol, the committee believes that individual members should have access to independent advice regarding their potential participation in medical research. The NHMRC National Statement suggests:

In the consent process, researchers should wherever possible invite potential participants to discuss their participation with someone who is able to support them in making their decision. Where potential participants are especially vulnerable or powerless, consideration should be given to the appointment of a participant advocate.<sup>11</sup>

5.27 The committee did not hear evidence of participant advocates being appointed elsewhere, however believes that this model may provide an opportunity to improve the consent process for ADF members considering whether to participate in research. The committee recommends that each prospective participant should have access to a private conversation with an independent participant advocate before providing their consent to participate. This person should be informed of the study protocol and have knowledge of the medical field, but should not be employed as part of the research team.

## **Recommendation 2**

**5.28 The committee recommends that all members of the Australian Defence Force who are invited to participate in medical research have access to a confidential conversation with an independent participant advocate prior to consenting to participate.**

### *Screening and post-trial communication processes*

5.29 The committee was concerned that a very small number of members participated in a trial even though their previous experiences of mental illness should have excluded them. The committee notes the development of the Defence eHealth System, and supports the IGADF recommendation that future trial investigators should be given access to the system to enable any relevant medical history of contraindicators to be identified at the time of obtaining a Defence member's consent to participate in a trial.<sup>12</sup>

5.30 The committee was also concerned to hear that some participants who withdrew from the trial early may have missed out on some of the follow up provided to other participants. However, the committee was reassured that these members would have still received the healthcare provided to all ADF members, including a

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11 *National Statement*, p. 68.

12 IGADF, *Inquiry report*, 2016, p. iii.

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medical examination at the end of deployment, two post deployment psychological screenings and annual health assessments while with the ADF.<sup>13</sup>

5.31 The committee heard some veterans faced distressing delays while waiting to receive information on their participation or otherwise in the trials. The committee supports efforts to improve this process. It notes the Defence eHealth System is likely to prevent future delays, as information on trial participation can be incorporated into the ADF members' medical records once the trial process has been concluded.

## **Assistance and support for veterans**

### ***Overarching need for assistance***

5.32 While the committee acknowledges the actions taken by Defence and DVA to address the concerns of veterans raised with the committee, the evidence to the committee indicated that either more needs to be done to assist veterans or done differently. Several witnesses who provided evidence were clearly in need of immediate assistance.<sup>14</sup> While there were some different views about the best and most appropriate ways to provide assistance and support, there was unanimous agreement that these veterans and their families need help. Therefore the focus of the committee was to look for new and different approaches to facilitate better support for this cohort and the wider veteran community.

5.33 The committee notes the commitments made and actions taken by the government in this area in response to the recommendations in the committee's report on veterans' mental health. However, the committee noted that despite these efforts, this cohort of veterans, at which the actions were directed, were mostly unaware of them. It was evident to the committee that additional support is necessary to address the issues faced by these veterans.

### ***Veterans' experiences with seeking assistance***

5.34 The clear message from Defence and DVA was that regardless of the cause of their symptoms, assistance is available. While this may be true it was not the experience for most individuals who spoke with the committee. 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.

5.35 Some individuals appeared to be accessing helpful assistance but unfortunately this was not a common experience for those who participated in the inquiry. The committee heard of a number of practical barriers that are inhibiting veterans accessing support, including cultural issues, unavailability of information and challenges accessing and navigating the DVA claims process as outlined below.

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13 Defence, *Submission 1*, p. 28.

14 DVA was in attendance at public hearings to provide assistance to veterans if required.

## ***Barriers to assistance***

### *ADF cultural issues*

5.36 The committee heard from veterans who either did not wish to engage with DVA as they had lost trust in the system or they found it difficult to ask for assistance as the culture of the ADF means there are barriers to self-reporting issues and vulnerability.

5.37 Acknowledging these cultural issues, it was suggested to the committee by a veteran that there needs to be more assistance and support when a soldier transitions to civilian life. To this end the committee notes the inquiry into transition from the ADF being undertaken by the Joint Standing Committee on Foreign Affairs, Defence and Trade which is examining support provided to members of ADF as they transition from active service to civilian life. The committee is not aware of the timeline for concluding the transition inquiry but recognises the importance of the issues and that this is a critical time for many veterans.

5.38 While the committee is concerned that some veterans do not wish to engage with DVA, the committee encourages those veterans to seek assistance. Although previous experience accessing assistance may not have been optimal, there have been a number of actions taken to improve services in recent years.

5.39 The committee was also reassured that when a veteran is ready to seek assistance, organisations such as the RSL and the Defence Force Welfare Association as well as a community of advocates and DVA officials are ready to help.

### *Provision of information*

5.40 Some suggestions for assistance focused on addressing some of the barriers reported by veterans to access information.

5.41 Veterans consistently told the committee that there is an ongoing need for information about a range of issues: details about their participation on the trials, information about the antimalarial medication they took and advice about what support and assistance is available. The committee recognises that both Defence and DVA have taken steps to make information available to veterans, by providing information about their trial participation, publishing information on websites and establishing a dedicated support team. It is important that these actions continue and are built upon.

### *Dedicated support line*

5.42 The dedicated mefloquine support line was a commitment by government as detailed earlier in this report. The committee received a number of accounts from witnesses which showed the support line has not been operating as effectively as it could. The committee was pleased to note that DVA has recognised this and taken action to make additional changes to ensure that veterans calling this line receive appropriate assistance. Given the consultation forums recently undertaken by DVA, there may be an increase in the number of calls made to the dedicated support line. Therefore, it is important that DVA ensures that staff working in that area receive

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ongoing training and information about these matters and are ready to provide details about available assistance.

### *DVA claims process*

5.43 The committee recognises that the DVA claims process can be difficult to navigate. Veterans reported that the process is particularly challenging when dealing with complex health conditions that cannot be linked to a single Statement of Principles. To this end the committee notes the evidence from the RMA that with assistance from an advocate to navigate the system there is often the ability to link some of their symptoms to service; however the committee notes the extraordinary length of time this can take for some.

5.44 The committee was pleased to note that DVA is conducting further investigation into the claims lodged relating to antimalarial medications since September 2016. The committee urges DVA to expedite this process and continue to offer these individuals either assistance from DVA or facilitate access to an advocate.

### **Recommendation 3**

**5.45 The committee recommends that the Department of Veterans' Affairs expedite their investigation on antimalarial claims lodged since September 2016 and continue to offer individuals assistance to lodge their claims and facilitate access to an advocate if required.**

### *Claims team*

5.46 Evidence from DVA detailed the composition of the Complex Case Team, noting that the seven delegates are supported by an EL1 Assistant Director, a contracted medical advisor and two social workers. The committee notes that delegates in this Complex Case Team also process claims relating to physical and sexual abuse in the ADF and are rotated after approximately 12 months.

5.47 The committee recognises that the Complex Case Team are dealing with challenging issues and that staff rotations are important to enable staff to take a break. However, the regular rotation of staff may result in loss of corporate memory. To ensure that all staff in the Complex Case Team consistently have an understanding of the issues identified by veterans in this inquiry, DVA needs to remain focused on providing ongoing training to staff.

5.48 In its report, *The Constant Battle: Suicide by Veterans*, the committee recommended that DVA conduct a review of its training programs for delegates and other staff dealing with veterans making claims for compensation and rehabilitation. While the committee recognises that this recommendation was accepted and progress against it has been reported as part of the estimates process, the committee again emphasises the importance of DVA officers working in the claims area undergoing ongoing training and support about issues facing veterans. The feedback from veterans following the recently held consultation forums may be instructive for the practices adopted by the Complex Case Team.

## **Recommendation 4**

**5.49 The committee recommends that the Department of Veterans' Affairs continue to provide ongoing training, information and support for the officers working in the Complex Case Team.**

### **Ensuring access to additional support and assistance**

5.50 Many of the identified barriers are familiar to the committee from its previous inquiries into similar issues, including its inquiry into veteran suicide. The committee has continued to monitor the implementation of the recommendations of that report through the estimates process. While the committee recognises that DVA is taking steps to streamline its systems and processes in order to provide better support for veterans and their families, it notes that results for veterans can take some time to flow through the system.

5.51 The committee notes that underlying some of these practical barriers is the stated need from some veterans and their families to have their symptoms recognised as being primarily caused by mefloquine and tafenoquine, a view not supported by the medical professionals (outlined in Chapter 2). As a committee of non-medical experts, the committee can only respect the view of the medical community. However, the committee notes the clear message from Defence and DVA that regardless of the cause, assistance is available.

5.52 Building on the initiatives already in place or underway, the committee has identified a number of areas for further improvement as outlined below. Due to the fact that these issues are affecting the veteran community, the committee's recommendations will necessarily be focused towards DVA.

### ***Information for and consultation with veterans and families***

5.53 A clear concern identified to the committee was the need to provide more information and support to families. If a veteran is unwell the burden of seeking assistance often falls to family members which, the committee heard, can sometimes mean seeking assistance from multiple agencies at the same time as providing direct care for a veteran. As with its previous inquiries, family members asked for support and information to be more readily available.

5.54 Family members identified that more tailored and coordinated support is needed particularly during times of crisis, when family members are primarily focused on addressing the immediate health needs of veterans and do not have the time and ability to seek advice about various support options. The committee heard that family members have received beneficial support from ex-service organisations but these services have not been provided in a coordinated manner. The committee sees the consultation forums being undertaken by DVA at various locations as a way to increase family members' awareness of short and long term assistance and how it can be accessed.

### ***Consultation***

5.55 It was clear to the committee that the previous commitment to an outreach program was interpreted differently in the veteran community. Most interpreted it as

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Defence or DVA contacting people individually who were involved in the trials. Defence was clear to the committee that it did not view this approach as beneficial as it does not wish to cause concern among veterans who are well. Defence emphasised that they will continue to provide information to trial participants upon request and provide support should there be concerns.

5.56 The committee understands the concerns raised by Defence about proactive outreach, but also understands that this veteran community will continue to call for what it considers to be an outreach program where soldiers involved in the trials are contacted. Noting this stalemate in positions, the committee supports the current round of consultation forums which is seeking to provide information to veterans about available assistance at the same time as receiving feedback from the veteran community.

#### *DVA consultation*

5.57 The recent consultation forums hosted by DVA in Adelaide, Melbourne and Townsville, as well as other locations nationally, provide a further opportunity for veterans and their families to access information and support from DVA. DVA advised that attendees at the first forum in Adelaide reported that it provided helpful information and was a good opportunity to openly discuss their concerns.

5.58 Given that Defence is continuing to provide information to veterans concerned about the use of antimalarials on its dedicated website, it would be beneficial for Defence officials to attend the consultation forums to maintain their knowledge of the issues raised by the veteran community and to update their website accordingly.

5.59 The committee is pleased that DVA remains open to expanding their consultation schedule and hosting additional events should there be sufficient interest. DVA is also seeking formal feedback from participants about their experience at the forum which will provide valuable insight about any changes that could be made to future forums. Given the complexity of some of the issues considered, it would be beneficial for consideration to be given to establish mechanisms to follow up matters raised by attendees, such as running a series of follow up events or a more individualised approach. As noted earlier, seeking assistance at a time of crisis is particularly challenging for families and the committee suggests that the consultation forums need to take account of the best ways to assist families at this time.

5.60 The committee recognises that some veterans may be unable, unavailable or currently unwilling to attend a consultation forum in the current schedule. The committee is of the view that information should be made available in a variety of ways to ensure that as many veterans as possible are able to access the information.

#### *Non-liability pathway*

5.61 Evidence from DVA highlighted that some veterans are unaware that access to mental health services is available under the non-liability pathway, with no requirement to link the condition to their service. In light of this, it would be beneficial for DVA to undertake an awareness raising campaign, targeted to the veteran community, to increase veterans' understanding of the non-liability pathway.

This campaign could be developed in consultation with advocates and ex-service organisations.

### **Recommendation 5**

**5.62** The committee recommends that the Department of Veterans' Affairs, in addition to the existing program of consultation forums, ensure matters raised by attendees and families are followed up. The forums should continue to be promoted widely and in consultation with ex-service organisations and advocate groups.

### **Recommendation 6**

**5.63** The committee recommends that the Department of Veterans' Affairs make the material provided at the consultation sessions available online.

### **Recommendation 7**

**5.64** The committee recommends that the Department of Defence attend the Department of Veterans' Affairs' consultation forums to maintain their knowledge of the issues raised by the veteran community. This will assist Defence to ensure their dedicated website is updated appropriately.

### **Recommendation 8**

**5.65** The committee recommends that the Department of Veterans' Affairs undertake a targeted awareness raising campaign, in consultation with ex-service organisations and veterans' advocates, to increase veterans' awareness of the non-liability pathway.

### *Assistance from General Practitioners*

**5.66** One of the key messages from Defence and DVA is that veterans who are concerned about their health should contact their GP. The Royal Australian College of General Practitioners (RACGP) and veterans also recognised the central role of GPs.

**5.67** Some veterans were concerned that their GP was not aware of mefloquine and tafenoquine and therefore was unable to provide the required assistance. Other witnesses described experiences when their GP had been helpful in terms of referrals and making connections with specialist services. The provision and regular review of information resources for GPs is important to ensuring that GPs are able to provide appropriate assistance to veterans and their families.

### *Information resources for GPs*

**5.68** The committee notes that DVA and Defence developed information resources for GPs about antimalarials and this material was distributed in 2016. The committee also notes that an information briefing for GPs was held in Townsville in 2016. The committee recognises that the actions taken to provide information to GPs are positive however some evidence provided to the committee suggested that veterans had experienced difficulties obtaining information from their GP. It would be beneficial for the information resources previously developed to be reviewed with particular advice for GPs to recognise the complex conditions with which some veterans may present.

5.69 Furthermore, given the recent TGA approval of tafenoquine, it may be beneficial for additional follow up information to be provided to GPs. This could build on information that will be sent to doctors from the pharmaceutical companies which will be producing tafenoquine.

5.70 The RACGP recognised that the provision of information about antimalarials is particularly relevant around major bases as well as in locations where there is a high volume of travel to and from malarial areas. In this context, it would be advantageous for DVA and the RACGP to take this into consideration when providing information.

5.71 The committee is pleased to note that a representative from the RACGP attends the DVA Health Providers Partnership Forum to provide advice about developing information resources for veterans. In addition, the committee is aware that the RACGP includes DVA information and resources in its publications distributed to the GP community. The continuation of this flow of information is important. Furthermore, the terms of reference of the Health Providers Partnership Forum indicate that the Forum can continue to provide a mechanism to update resources and facilitate information sharing.

#### **Recommendation 9**

**5.72 The committee recommends that the Department of Veterans' Affairs and Department of Defence, in collaboration with the Royal Australian College of General Practitioners and other health professionals, review and update the clinical guidelines developed in 2016 to recognise the complex conditions with which some veterans may present.**

#### **Recommendation 10**

**5.73 The committee recommends that the Department of Veterans' Affairs consult with the Royal Australian College of General Practitioners to assess whether General Practitioner briefings, like the one that occurred in Townsville in 2016 would be beneficial in other areas, including around major bases.**

#### ***The need for multidisciplinary care***

5.74 The other need which was evident to the committee is that these veterans are dealing with complex and sometimes chronic health needs which require more than a visit to a GP or one specialist to receive a diagnosis. In this context, the committee supports the need for multidisciplinary care. The committee is pleased to note that DVA has recognised that some individuals need tailored, wrap around assistance and that this may need to include supports from a range of specialists to address their complex needs.

#### ***Additional research***

5.75 The committee is aware that Defence and DVA have jointly commissioned the University of Queensland to undertake a research study looking at the self-reported health of ADF personnel using antimalarials on deployment. This research will use de-identified data from a number of the trials. DVA advised that this new research will focus on the health outcomes of deployed veterans who took antimalarial medications.

5.76 It is expected that this research study will be completed later in 2018. The committee anticipates that the findings from this research may be instructive for DVA in the context of developing services and support that address the challenges reported by this cohort of the veteran community.

### **Recommendation 11**

**5.77 The committee recommends that the Department of Veterans' Affairs review the University of Queensland research findings due in late 2018 with a view to further inform the development of any new initiatives and the ongoing review of existing programs.**

#### ***Neurocognitive Health Program***

5.78 As outlined in Chapter 2, veterans suffering from chronic and complex conditions have attributed their symptoms to taking mefloquine or tafenoquine some time ago. The committee heard from individuals that, as many of these reported symptoms are similar to symptoms of PTSD, this has led to veterans being misdiagnosed with PTSD, receiving treatment for PTSD which ultimately has not been successful. While many witnesses including Dr Nevin could not name a specific treatment that veterans attributing poor health to taking antimalarials should be receiving, the committee heard that they are particularly concerned about possible neurocognitive effects.

5.79 Recognising that this is an area which DVA does not have much expertise, DVA has committed to the development of a program to deal with neurocognitive issues, regardless of the cause. This new Neurocognitive Health Program will be accessible to all veterans who have been assessed as requiring treatment for neurocognitive issues.

5.80 The committee is pleased to note that Professor McFarlane and the AQVFA are involved in the design of this program which will add to the range of assistance available from DVA. The committee supports the development of this program, recognising the value of developing treatment and services through a model of co-design.

5.81 Given the potential positive impact of the program, the committee is of the view that its development should be given a high priority. As a first step, the committee encourages DVA to consider early rollout to a targeted population as a pilot program. The pilot program could then be formally evaluated to inform further development of the program prior to broader rollout.

### **Recommendation 12**

**5.82 The committee recommends that the Department of Veterans' Affairs prioritise the development of the Neurocognitive Health Program. To enable veterans to access this program as soon as possible, consideration should be given to the rollout of a pilot program to a targeted population.**

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**Recommendation 13**

**5.83 The committee recommends that the pilot program undertaken as part of the Neurocognitive Health Program be formally evaluated and that the evaluation report be made publicly available.**

*Collaborative working group*

5.84 The committee recognises the importance of fostering cooperation and collaboration between DVA and the veteran community and supports the development of the Neurocognitive Health Program. As stated above, the committee has recommended that a pilot program be considered which would subsequently be evaluated. The post evaluation stage provides another opportunity for DVA to further engage with the veteran community.

5.85 In this context, the committee suggests that a collaborative working group be established to consider the outcomes of the pilot as well as how best to roll out the program more broadly to the veteran community, should it be supported. The establishment of this group could provide another means of facilitating an ongoing dialogue between DVA and veterans. Given the concerns raised by some veterans in the inquiry about the challenges they have experienced when accessing assistance and support, the committee considers that the collaborative working group model could provide a means of further improving relationships and enhancing trust between veterans and the organisations supporting them.

**Recommendation 14**

**5.86 The committee recommends that, following the evaluation of the Neurocognitive Health Program pilot, a collaborative working group be established, including those who contributed to the development of the program, veterans and advocates, medical professionals and the Department of Veterans' Affairs. This group would consider the outcomes of the pilot and, if supported by the evaluation, how best to roll out and promote the program to all veterans it could assist.**

**Senator Alex Gallacher**

**Chair**

