

# A Survey of Australian patient preferences regarding subcutaneous erythropoiesis-stimulating agents

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## Abstract:

**Background:** Understanding patient treatment preferences may help enhance compliance, empower patients and improve clinical outcomes. We surveyed adult patients with renal anaemia to investigate 1) the extent to which injection site pain and dosing frequency influence patient preferences regarding subcutaneous (sc) erythropoiesis-stimulating agent (ESA) treatment and 2) the practice pattern of how sc ESAs are used in Australia.

**Methods:** Adult patients with chronic kidney disease, who were receiving sc ESA, were recruited from renal units at seven sites in Australia. Patients were surveyed by independent, trained and accredited interviewers using a standardised, 20-item questionnaire.

**Results:** Of the 101 patients recruited, half (n = 55) experienced injection site pain. Slight, moderate or significant pain was reported by 27% of patients on darbepoetin alfa, 29% on epoetin alfa and 8% on epoetin beta. Patient preferences were influenced by injection site pain and dosing frequency; more than half (n = 58) of the patients reported that less injection site pain and less frequent injections would represent meaningful improvements in sc ESA treatment. Most (n = 64) patients indicated that they would be comfortable discussing sc ESA treatment options with their doctor. Patients were following current Australian treatment guidelines for sc ESA use. Most patients self-administered their sc ESA into their abdomen once weekly.

**Conclusions:** In our study, patient preferences regarding sc ESA were influenced by injection site pain and dosing frequency. Patients were following Australian treatment guidelines. We encourage healthcare professionals to promote patient empowerment and advocate patient preferences regarding sc ESA treatments.

## Key Words

Anaemia kidney failure, chronic, erythropoietin, recombinant. Injections, subcutaneous. patient participation

2008; Eprex Product Information, 2008; NeoRecormon Product Information, 2008). Unfortunately, injection site pain is a common adverse event associated with sc ESA administration.

Not all ESAs produce the same magnitude of effect on injection site pain following sc administration. Clinical trials have shown that sc administration of epoetin beta is less painful than sc administration of either epoetin alfa or darbepoetin alfa (Frenken et al., 1991; Granolleras et al., 1991; Schmitt et al., 2006; Vanrenterghem et al., 2002; Veys et al., 1998; Veys et al., 1992), and that sc darbepoetin alfa is significantly more painful than either sc saline or sc continuous erythropoietin receptor activator (Pannier et al., 2007). Understanding a patient's response to injection site pain is important because injection site pain is a factor that contributes to sc ESA non-compliance (Wazny et al., 2002).

In addition to patient compliance, injection site pain may also influence a patient's preference for a particular ESA treatment. A recent Australian study comparing injection site pain following sc administration of epoetin beta or darbepoetin alfa found that sc injection of

## Introduction

Current international (KDOQI 2007; Locatelli et al., 2004; Moist et al., 2008) and Australian (Kidney Health Australia 2008) treatment guidelines recommend subcutaneous (sc) erythropoiesis-

stimulating agent (ESA) administration for the treatment of anaemia in all patients with chronic kidney disease, except those receiving haemodialysis. In most patients, ESAs must be dosed frequently to maintain efficacy (Aranesp Product Information,

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epoetin beta was significantly less painful than darbepoetin alfa and that patients preferred epoetin beta (Roger et al., 2008). These results suggested that the difference in injection site pain was clinically meaningful (Roger et al., 2008). To date, limited data are available that examine the impact of injection site pain and its corollary, frequency of administration, on patient preference for sc ESA treatment. Understanding patient preferences for sc ESA treatment is important for individualizing patient treatment decisions, ensuring compliance, enhancing patient satisfaction and empowering patients (Caress et al., 2005; Davison et al. 1997; Degner et al., 1997; Krahn et al., 2008). These patient-focused outcomes are recognized as being particularly beneficial for the management of chronic disease and can be associated with improved clinical outcomes.

In the current study, we surveyed adult patients with renal anaemia to understand 1) the extent to which factors including injection site pain and dosing frequency cause patients concern or discomfort, and influence patient preference of sc ESA treatment and 2) the practice pattern of how sc ESA is used in Australia in terms of the type of ESA received, the frequency of administration, the injection site location and who administers the ESA.

### Methods

#### Patients

Adult patients with chronic kidney disease currently receiving an ESA via sc administration were invited to participate in a patient survey at the time of their visit to their renal unit. Seven sites in three Australian states participated in this study.

#### Data collection

Patients were interviewed between February and April 2008. The interviews were conducted independently by fully trained and accredited interviewers using a standardised 20-item questionnaire (Box 1). All interviews were conducted in accordance with the ethical guidelines recommended in the Australian Market and Social Research Society Code of Professional Behaviour and each interview took approximately 10 minutes.

**Table 1. Patient characteristics**

Characteristic	Total population ( <i>n</i> = 101)	Patients stratified by ESA treatment			
		Epoetin beta ( <i>n</i> = 12)	Darbepoetin alfa ( <i>n</i> = 66)	Epoetin alfa ( <i>n</i> = 17)	ESA unknown ( <i>n</i> = 6)
Sex, <i>n</i>					
Male	61	9	34	14	4
Female	40	3	32	3	2
Dialysis status, <i>n</i>					
Not on dialysis	46	11	20	11	4
Peritoneal dialysis	54	1	45	6	2
Haemodialysis	1	0	1	0	0
Comorbid diabetes, <i>n</i>					
No diabetes	64	6	43	12	3
Type I diabetes	12	1	6	2	3
Type II diabetes	20	4	13	3	0
Has diabetes; patient unsure of type	2	1	1	0	0
Patient does not know if they have diabetes	3	0	3	0	0

Abbreviation: ESA, erythropoiesis-stimulating agent

During the structured interview, patients were asked about: their current ESA use; the extent to which sc ESA administration caused them concern, discomfort or pain; their preference regarding ESA treatment; and their involvement in ESA treatment decisions. The only questions asked of the patients were those described in the questionnaire. Some questions were only asked if patients gave a certain response to one or more previous questions. To minimise the impact of context effects, the questions were administered in the same order to all patients.

#### Data analysis

Descriptive statistics are presented for each item included in the questionnaire.

### Results

#### Patient demographics and sc ESA practice patterns in Australia

A total of 101 patients were included in the study (Table 1); approximately half (*n* = 55) were on dialysis. Practice patterns of sc ESA administration were consistent

with international and Australian guidelines. Of the 101 patients, most (*n* = 78) were receiving either darbepoetin alfa (*n* = 66) or epoetin beta (*n* = 12); a minority (*n* = 6) were not sure what ESA they were currently receiving. Interestingly, approximately one in five patients (*n* = 17) were receiving epoetin alfa. Most patients self-administered their ESA into their abdomen at a frequency of once weekly (Table 2).

#### Cause of pain, discomfort or concern from current ESA

Approximately one in every two patients (*n* = 55) experienced some degree of pain or discomfort with their ESA injection. When the patient responses were stratified by ESA treatment, sc epoetin beta administration was associated with the lowest degree of pain or discomfort while sc darbepoetin alfa was associated with the highest degree of pain or discomfort (Figure 1).

Most patients did not inform others about the pain or discomfort that the

**Table 2. Current ESA treatment**

Characteristic	Total population (n = 101)	Patients stratified by ESA treatment			
		Epoetin beta (n = 12)	Darbepoetin alfa (n = 66)	Epoetin alfa (n = 17)	ESA unknown (n = 6)
Frequency of administration, n					
Once weekly	50	7	30	8	5
Fortnightly	33	3	26	3	1
Monthly	8	0	5	3	0
Other	10	2	5	3	0
Location of injection, n*					
Abdomen	79	11	50	14	4
Thigh	14	1	11	0	2
Arm	12	0	7	5	0
Who administers the injection, n					
Self	65	9	43	9	4
Carer	17	0	12	4	1
Hospital nurse	1	0	0	0	1
Other nurse	8	2	4	2	0
General practitioner	9	1	6	2	0
Someone else	1	0	1	0	0

Abbreviation: ESA, erythropoiesis-stimulating agent

\* Some patients reported more than one injection site so numbers reported exceeds that of the total population.

ESA injection causes them. Of the 35 patients who were asked to answer this question based on their previous response (Box 1 – see question 10b), 20 did not tell anyone; the remaining 15 patients either told the general practitioner (n = 5), specialist (n = 3), hospital nurse (n = 2) or someone else (n = 5).

Injection site pain and discomfort concerned some patients (n = 33). Many (n = 23) of these patients indicated that they felt anxious about receiving their ESA injection. Most (n = 20) of these 23 patients reported that their level of anxiety was minor or that they had learned to cope with it.

**Patient preference for ESA treatment: injection site pain and discomfort**

Approximately one in every two patients (n = 52) would be more comfortable receiving their current ESA if it caused

less pain and discomfort. Interestingly, patients’ responses to this question appeared to depend upon the ESA being received. Stratifying patient responses by their current treatment revealed a differential pattern of response with each ESA (Figure 2). Of the 66 patients receiving darbepoetin alfa, the majority (n = 40) responded that they would be more comfortable receiving this treatment if it caused less pain and discomfort. In contrast, of the 17 patients receiving epoetin beta, only a minority (n = 3) responded that they would be more comfortable receiving this treatment if it caused less pain and discomfort.

When patients were asked to consider their original treatment decision, almost half (n = 48) of the patients responded that, if their doctor had given them the option, they would have chosen an ESA that was associated with less pain and

discomfort instead of their current ESA. Again, patients’ responses to this question appeared to depend upon the ESA being received (Figure 3). When patients’ responses were stratified by their current treatment, the pattern of responses showed that more patients currently receiving either darbepoetin alfa or epoetin alfa, than patients receiving epoetin beta, would have chosen an ESA treatment associated with less pain and discomfort (Figure 3).

A similar pattern of response was apparent when patients were asked to consider a decision about their current treatment (Figure 4). More patients receiving darbepoetin alfa or epoetin alfa, than patients receiving epoetin beta, indicated a preference to receive an ESA with less injection pain instead of their current ESA (assuming the putative ESA was equally effective, safe and administered at the same frequency as their current ESA) (Figure 4).

**Patient preference: frequency of administration**

The frequency of ESA administration was also an important factor in determining patient preference for ESA treatment, particularly for those patients receiving darbepoetin alfa. When patients were presented with the option of receiving an equally effective ESA that 1) was associated with less pain and discomfort and 2) required fortnightly administration, more than half (n = 58) of the patients said that they would prefer to receive that ESA instead of their current ESA. For the patients receiving darbepoetin alfa, the addition of the option for fortnightly administration to the option of receiving an equally effective ESA associated with less pain and discomfort increased patient preference from 43.9% to 62.1%. For the patients receiving epoetin alfa and epoetin beta, this additional option increased patient preference by 12% and 16%, respectively.

**Patient preference: factors that would improve ESA treatment**

Patients indicated that there is room for improvement in ESA treatment. An ESA that caused less pain would be viewed by 36.6% (n = 37) of patients as providing a meaningful improvement in ESA treatment. An ESA that had to be injected less often would be viewed by 33.7% (n = 34) of patients as providing a meaningful improvement in ESA treatment. An ESA that could be left out of the refrigerator for longer would be viewed by 13.9% (n = 14) of patients as providing a meaningful improvement in ESA treatment.

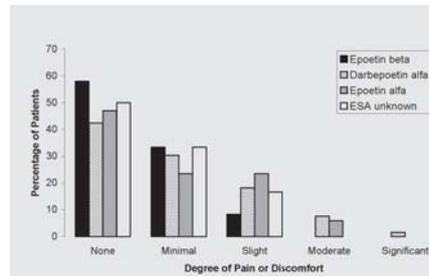
Approximately one-third of patients (n = 38) responded that ‘something else’ would result in a meaningful improvement in ESA treatment. However, of these patients, the majority (n = 35) expressed satisfaction with their current ESA treatment and did not identify any other parameters that would improve ESA treatment.

**Patient preference: involvement in ESA treatment decisions**

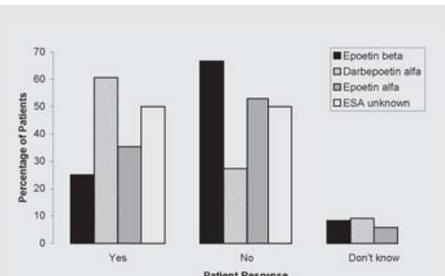
When patients were asked if they would be comfortable discussing the different ESA options with their doctor, the majority (n = 64) said yes.

**Discussion**

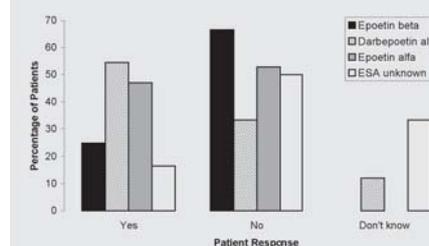
Very few studies have investigated patient preferences regarding sc ESA treatment. Our study demonstrates that both injection site pain and its corollary, frequency of ESA administration, contribute to patient preferences regarding ESA treatment. Notably, patients would prefer to have less painful and less frequent injections. Although patients indicated that they would be comfortable discussing the different ESA options with their doctor, our research suggests that few currently do. Consistent with international and Australian guidelines, most patients in our study self-administered their ESA into their abdomen once a week. Our research provides unique information about patient preference and suggests that patients would like to be involved in their ESA treatment decisions. We encourage healthcare professionals to empower patients



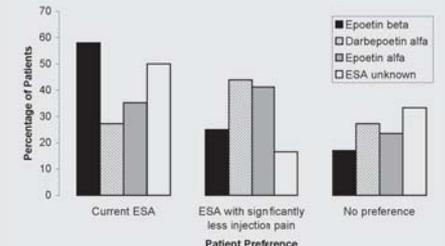
**Figure 1.** The degree of pain or discomfort patients experience with their current ESA treatment.



**Figure 2.** Patient comfort with their current ESA treatment. Patients were asked if they would be more comfortable receiving their ESA if it caused less pain and discomfort. Possible responses were: yes, no, don't know.



**Figure 3.** Patient preferences regarding original treatment decision. Patients were asked to consider their treatment decision at the time they had initiated ESA treatment. If the patients had been offered an ESA that causes less pain and discomfort (that was equally effective, safe, and administered at the same frequency), would they have chosen that ESA instead of the ESA that they were currently receiving. Possible responses were: yes, no, don't know.



**Figure 4.** Patient preferences regarding current treatment decision. When considering their current treatment, patients were asked what ESA they would prefer if an ESA was now available that caused significantly less pain and discomfort (assuming the ESA was equally effective, safe, and administered at the same frequency). Possible preferences were: current ESA, ESA that caused significantly less pain and discomfort, no preference, don't know.

and advocate patient preferences when considering ESA treatment options.

Our finding that injection site pain influences patient preference for sc ESA treatment is consistent with the findings from a recent study comparing injection site pain following sc administration of epoetin beta or darbepoetin alfa (Roger et al., 2008). However, our finding contrasts with results from an earlier study conducted by the American Association of Kidney Patients which reported that the majority of patients (61%) felt that the possibility of injection pain was of no or little importance when choosing to receive an ESA via sc or intravenous injection

(American Association of Kidney Patients 1997). Notably, this study evaluated patient preferences when sc ESA treatment options were limited. Injection site pain may impact patient treatment preference less when choosing between the sc or intravenous administration than when choosing between a variety of sc ESA treatment options.

Approximately one in every two patients in our study reported that they experience injection site pain, which caused some patients to feel anxious about their treatment. Most patients were reluctant to inform anyone about the pain or discomfort their sc ESA treatment caused

them. As a result, healthcare professionals are likely to be unaware of their patients' concerns about sc ESA treatment. To bridge this gap in communication, we would encourage the prescribing clinician to initiate a discussion about ESA treatment choices and allow patients to make an informed treatment decision.

We also found that patients' concerns with injection site pain were less pronounced in patients receiving epoetin beta than in patients receiving either darbepoetin alfa or epoetin alfa. In this regard, our results are consistent with results from other studies showing that sc administration of epoetin beta is less painful than either epoetin alfa or darbepoetin alfa (Frenken et al., 1991; Granolleras et al., 1991; Schmitt et al., 2006; Vanrenterghem et al., 2002; Veys et al., 1998; Veys et al., 1992).

The impact of the frequency of ESA administration on patient preference may be related to the desire to avoid injection and the associated pain. Although the majority of patients would prefer to receive an ESA that would be administered less often, the frequency of administration appeared to be of most concern to patients receiving darbepoetin alfa. A large proportion (58%) of patients receiving darbepoetin alfa reported pain associated with injection; a large proportion (44%) of these patients also expressed preference for a treatment associated with less injection site pain. Our results suggest that it might be particularly helpful for patients receiving darbepoetin alfa and their healthcare professionals to discuss the risks and benefits of changing to an ESA treatment that may cause less pain and require fewer injections.

For patients with chronic kidney disease, the management of renal anaemia may be only one of the many conditions for which they are being treated. Shared care and decision-making are recognised as beneficial to the management of chronic diseases (Kaplan et al., 1989; DiMatteo et al., 1994). When the patient takes a more active role in their healthcare decisions, the

healthcare professional becomes increasingly responsible for finding out what patients want, providing them with the appropriate information and supporting them in the decision making process (Krahn et al., 2008). The results from this study provide the busy healthcare professional with both a rationale to consider including the patient in ESA treatment decisions and much-needed information regarding patient preference for sc ESA treatment.

In terms of limitations, we recognise that our study had a relatively small sample size and issues concerning patient background (e.g., age, level of education) were not taken into account. These factors could limit the generalisability of our results. However, our study was conducted at multiple sites across Australia and, to this end, we believe our results offer useful insight into Australian patient preferences regarding sc ESA treatment.

We also acknowledge that we did not use a validated scale to assess patient preferences. To the best of our knowledge, however, there are no validated scales that assess the influence of injection site pain and frequency of administration on patient preferences. In addition, although no statistical analyses were performed, we believe that communicating the results of the study in a descriptive manner still provides the medical community with important, unique information about the patient's perspective that could be incorporated into everyday practice to potentially improve patient satisfaction.

### Conclusions

This research demonstrates that patient preferences regarding sc ESA treatment are influenced by injection site pain and frequency of administration. Patients would prefer less painful and less frequent injections, but few patients discuss these preferences with their prescribing healthcare professional. These findings underscore the need for prescribing healthcare professionals to promote patient empowerment and advocate patient preferences regarding sc ESA treatment. We encourage prescribing

healthcare professionals to initiate a discussion about sc ESA treatment options with their patients and to take patient preferences into account when making sc ESA treatment decisions.

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## Box 1. Questionnaire items

### Q1: RECORD GENDER

Male	<input type="checkbox"/> 1
Female	<input type="checkbox"/> 2

### Q2: RECORD DIALYSIS

Not on dialysis	<input type="checkbox"/> 1
Peritoneal dialysis	<input type="checkbox"/> 2
Haemodialysis	<input type="checkbox"/> 3

### Q3: Are you a diabetic?

If "yes", probe for type

Type I diabetic (insulin dependent)	<input type="checkbox"/> 1
Type II diabetic	<input type="checkbox"/> 2
Diabetic – do not know type	<input type="checkbox"/> 3
Not a diabetic	<input type="checkbox"/> 4
Don't know	<input type="checkbox"/> 5

### Q4a: Which ESA are you currently receiving? ESA is also known as EPO, or as erythropoietin.

Aranesp (darbepoetin alfa)	<input type="checkbox"/> 1
Eporex (epoetin alfa)	<input type="checkbox"/> 2
NeoRecormon (epoetin beta)	<input type="checkbox"/> 3
(DO NOT READ OUT)	
Don't know	<input type="checkbox"/> 4

For those patients who answered Aranesp to Q4a, ask the following:

### Q4b: Are you using the Aranesp SureClick pen?

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

### Q6: How often you receive your ESA?

Once a week	<input type="checkbox"/> 1
Fortnightly	<input type="checkbox"/> 2
Monthly	<input type="checkbox"/> 3
Some other duration (specify)	<input type="checkbox"/> 4

### Q7: Who most commonly administers your ESA injections?

Self	<input type="checkbox"/> 1
Carer (such as relative, friend or partner)	<input type="checkbox"/> 2
Hospital nurse	<input type="checkbox"/> 3
Some other nurse	<input type="checkbox"/> 4
General practitioner (GP)	<input type="checkbox"/> 5
Someone else (specify)	<input type="checkbox"/> 6

### Q8: What location do you administer your ESA injection?

Abdomen	<input type="checkbox"/> 1
Thigh	<input type="checkbox"/> 2
Arm	<input type="checkbox"/> 3

### Q9: If you had a choice, what would you consider to be a meaningful improvement to your treatment?

One which causes less pain or discomfort upon injecting	<input type="checkbox"/> 1
One which had to be injected less often	<input type="checkbox"/> 2
One which could be left out of the refrigerator for longer	<input type="checkbox"/> 3
Something else (specify)	<input type="checkbox"/> 4

### Q10a: To what extent do you find your ESA causes you pain or discomfort on injection? Would you say it causes you .....

Significant pain	<input type="checkbox"/> 1
Moderate pain	<input type="checkbox"/> 2
Slight pain	<input type="checkbox"/> 3
Minimal pain	<input type="checkbox"/> 4
No pain at all	<input type="checkbox"/> 5

**Q10b: Have you ever found your ESA to hurt or cause discomfort when injected?**

Yes	<input type="checkbox"/> 1
No (If no go to Q 15.)	<input type="checkbox"/> 2

**Q11: And, when ESA is injected, how often does it hurt or cause discomfort?**

Every time	<input type="checkbox"/> 1
Most times	<input type="checkbox"/> 2
Sometimes	<input type="checkbox"/> 3
Not very often	<input type="checkbox"/> 4
Never	<input type="checkbox"/> 5

**Q12: Which of the following statements would you say best describes the level of anxiety injecting your ESA causes you.**

I worry about it, and it makes me nervous	<input type="checkbox"/> 1
I can be anxious, but it is not too bad	<input type="checkbox"/> 2
It bothers me a little, but have learnt to cope with it	<input type="checkbox"/> 3
It only bothers me very slightly	<input type="checkbox"/> 4
It does not bother me at all	<input type="checkbox"/> 5

**Q13: Have you discussed the pain or discomfort of your ESA injection with any of the following people?**

Hospital nurse	<input type="checkbox"/> 1
General practitioner / GP	<input type="checkbox"/> 2
Someone else (specify)	<input type="checkbox"/> 3
No one	<input type="checkbox"/> 4

*If answer to Q13 included specialist, nurse or GP:*

**Q13a: Having discussed (ANSWER FROM Q12) the pain your ESA can cause, what action (if any) was taken? What, if anything, did they suggest or recommend?**

*If answer to Q14 did not include specialist, nurse or GP:*

**Q14: What are the main reasons why you have not mentioned the pain your ESA can cause to a doctor or nurse?**

**Q15: Would you be comfortable to have your doctor talk to you about the differences between ESAs, so you could be involved in choosing your treatment?**

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2

**Q16: Thinking back to when you first started taking ESA, if your doctor had offered you an ESA which causes less pain and discomfort, would you have chosen it instead of the ESA you are currently taking (assuming it was equally effective, equally safe and was administered with the same frequency)?**

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

**Q17: Would you be more comfortable receiving your current ESA, if it caused less pain or discomfort?**

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

**Q18: And, if there was an ESA available now which causes less pain and discomfort, which would you most likely prefer (assuming both were equally effective, equally safe and were administered with the same frequency)?**

Current ESA	<input type="checkbox"/> 1
ESA which causes significantly less pain and discomfort	<input type="checkbox"/> 2
No preference	<input type="checkbox"/> 3
(DO NOT READ OUT) Don't know	<input type="checkbox"/> 4

**Q19: Would you prefer to receive once weekly injections with less injection pain, instead of your current ESA?**

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3

**Q20: Would you prefer to receive fortnightly injections with less injection pain, instead of your current ESA?**

Yes	<input type="checkbox"/> 1
No	<input type="checkbox"/> 2
Don't know	<input type="checkbox"/> 3



## RSA Journal Cover Photos Wanted

Do you have a photo/picture for the front cover of the RSAJ? If yes, please email to paul.bennett@flinders.edu.au. (Please note that consent is required all people identified in photographs used in The RSAJ).