

Management of the Australian Q Fever Register for 2016-17

MILESTONE REPORT 13: Quarterly register operation

PROJECT CODE: 2017-1028

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DATE SUBMITTED: June 2017

DATE PUBLISHED: December 2017

PUBLISHED BY: AMPC

The Australian Meat Processor Corporation acknowledges the matching funds provided by the Australian Government to support the research and development detailed in this publication.

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1.0 EXECUTIVE SUMMARY

The Australian Q Fever Register (the Register) is the first non-statutory health register to be established in Australia and has been operating without interruption since 2001. It provides a secure repository of records documenting the Q Fever status for individuals as an aid for the meat industry in managing workplace health risks from Q Fever and, in addition, serves as a valuable and unique resource of data for researchers.

The Register is operating in changing regulatory and technological environment. Uncertainties surrounding its continued existence and funding drove investigations during 2016-17 into the possibility of its ultimate inclusion in the Australian Immunisation Register (AIR), and consideration of alternate models of funding. Although the long-term future of Q fever immune status and vaccination records appear to lie within the AIR, this solution neither addresses short-term funding imperatives nor ensures access of either registered individuals or medical practitioners to historical immune status and vaccination records.

2.0 INTRODUCTION

Q Fever is a highly infectious zoonotic disease. The risk of infection is linked to occupation with the highest occupational exposure risks reported for people associated with the meat processing industry, followed by the general agricultural livestock industry. Most affected people recover, but a small proportion may suffer severe and chronic debilitating disease, and in rare instances the disease may cause fatality. Work-related disease (acute or chronic) due to Q Fever represents a substantial economic cost to the industry from time off work.

A Q Fever vaccine has been available in Australia since 1989 and has been shown to be highly protective. The Commonwealth-funded National Q Fever Management Program (QFMP) was run from 2001 to 2006 largely to increase vaccine uptake in people most likely to be exposed to the disease.

The Australian Q Fever Register (the Register) was initiated in 2001 to serve as a secure repository of records documenting the Q Fever status for individuals as an aid for the meat industry in managing workplace health risks from Q Fever. In addition to this important service to industry, the Register provides a valuable source of data for researchers.

The Register is run from premises in Canberra.

3.0 PROJECT OBJECTIVES

The project objectives are to:

- a) Manage the Australian Q Fever Register and associated help-line services to provide a reliable record of Q Fever immune status for individuals as part of effective Q Fever risk management in the workplace.
- b) Ensure the Australian Q Fever Register continues to operate in compliance with Australian Privacy Principles and with relevant recommendations concerning Q Fever testing and vaccination.

c) Prepare the transition of the funding of the Q Fever Register to a new model.

4.0 METHODOLOGY

The Australian Q Fever Register (the Register) is the first non-statutory health register to be established in Australia and has been operating without interruption since 2001.

The Register can be accessed via the internet at www.qfever.org. Register staff provide a help-line service during work hours.

The purpose of the Register is to provide a secure repository of information about the Q Fever immune status of individuals as an aid in managing workplace health and safety.

The Register provides a permanent and secure repository of an individual's Q Fever status, ensuring that individuals only need to be tested and vaccinated once as per current health recommendations. This is an important contribution to lowering health risks by ensuring that individuals do not inadvertently get tested or vaccinated more than once, procedures that may in some cases result in adverse side effects.

Once an individual's Q Fever status is entered into the Register and reconciled, a Q Fever card is produced by the Register and mailed to the individual. The card is a durable plastic card the size of a credit-card, printed with indelible ink. The card provides a permanent record of the individual's name, Q Fever number and Q Fever status that can be carried by the individual and displayed on request.

Figure 1 Image of a printed Q Fever card issued by the Q Fever Register



Any individual whose details have been entered onto the Register can ring the Register during work hours and ask for a replacement card to be printed and sent or ask for an immediate printed Q Fever status report to be sent by email or fax as evidence of their Q Fever status. With an individual's consent, an authorised employer may check an individual's Q Fever status as well by calling the Register helpline or through the Q Fever website.

The Register is voluntary meaning that information about any individual can only be entered into the Register if that individual signs a consent form authorising use of their personal information.

The Register adheres to strict privacy guidelines to ensure the security and privacy of personal information held on the Register. The database and website are highly secure, with all data being encrypted during transmission. User registration procedures, password access, internal quality assurance procedures and data auditing facilities all combine to ensure the best possible data quality and protection of personal information. The Register complies with the Australian Privacy Principles (APPs) in the Privacy Act 1988 (Cth).

The Register provides the following general services and information:

- a public website providing information about Q Fever and about the Register that can be accessed by anyone with an internet-capable computer or device
- a help-line and email contact system allowing anyone to contact the Register to ask for information about the Register and about their Q Fever status
- a password-controlled section of the website controlled by Register staff who can issue registered users with password access to secure parts of the website where they can either upload information from individuals being entered onto the Register for the first time, or check an individual's Q Fever status provided they have been given authorisation by the individual concerned
- a password-controlled administrative section of the website that can only be accessed by Q Fever staff and that allows records to be entered, checked and reconciled, and Q Fever cards or status reports and other outputs to be generated.

5.0 PROJECT OUTCOMES

5.1 Register Operations

As at 28 June 2017, the Register held the vaccination and/or immune status of 169,450 individuals.

A total of 18,594 individuals were added to the Register between 1 July 2016 and 28 June 2017.

5.1.1 Registrations by financial year

Activity in the 2016-17 financial year was the second-highest in the sixteen years of Register operation, exceeded only by the preceding 2015-16 year.

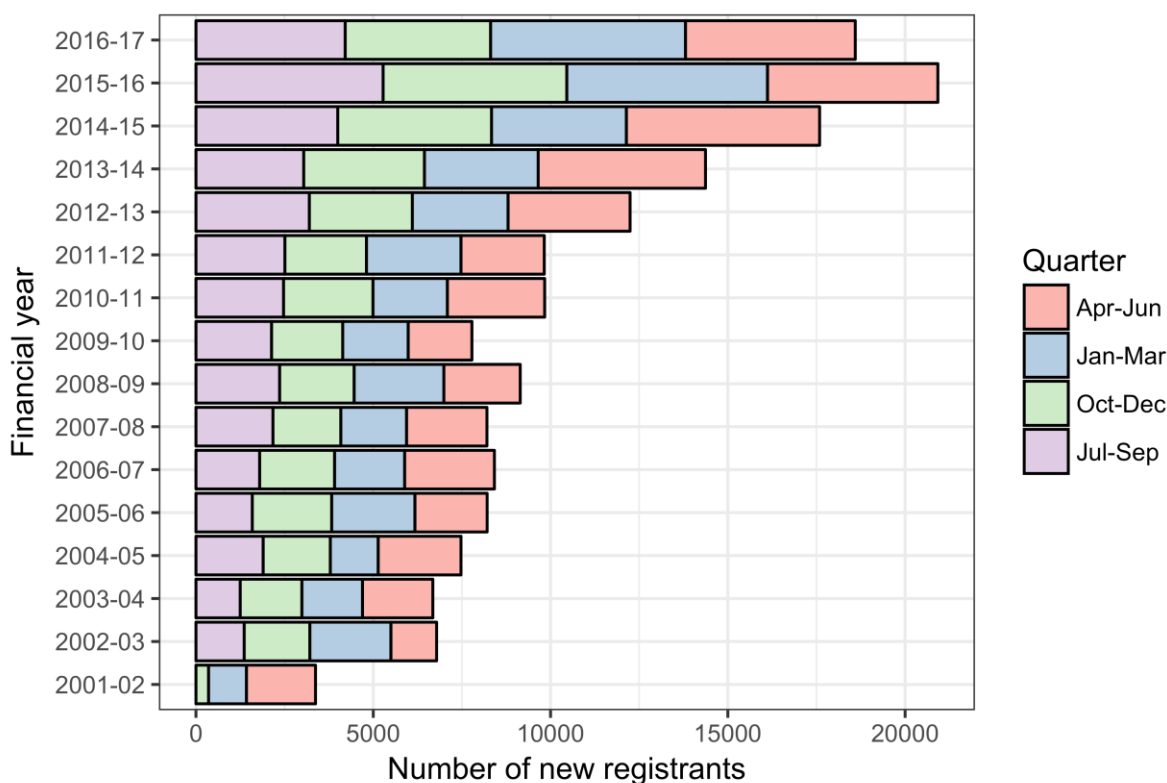


Figure 2 New Australian Q Fever Register registrations, by financial year and quarter.

5.1.2 Source (state of residence) of Registrants

Registrations have been received from all Australian states and territories (Table 1). Overall, more than 90% of registrations derive from QLD, NSW and VIC (Table 1); however, the proportions from each jurisdiction have changed over time (Figure 3 and Table 2), with Victoria, particularly, increasing and Qld decreasing their proportional representation .

Table 1 Overall percentage of Q Fever Register registrations from 2002 to 28 June 2017, by state

| ACT | NSW | NT | QLD | SA | TAS | VIC | WA | Other |
|-----|------|-----|------|-----|-----|------|-----|-------|
| 0.4 | 23.2 | 0.4 | 51.6 | 3.7 | 0.7 | 16.3 | 3.6 | 0.0 |

Table 2 Percentage of Q Fever Registrations by state in 2017 (1 January to 28 June 2017)

| ACT | NSW | NT | QLD | SA | TAS | VIC | WA | Other |
|-----|------|-----|------|-----|-----|------|-----|-------|
| 0.8 | 29.4 | 0.6 | 32.3 | 7.4 | 0.7 | 25.5 | 3.0 | 0.3 |

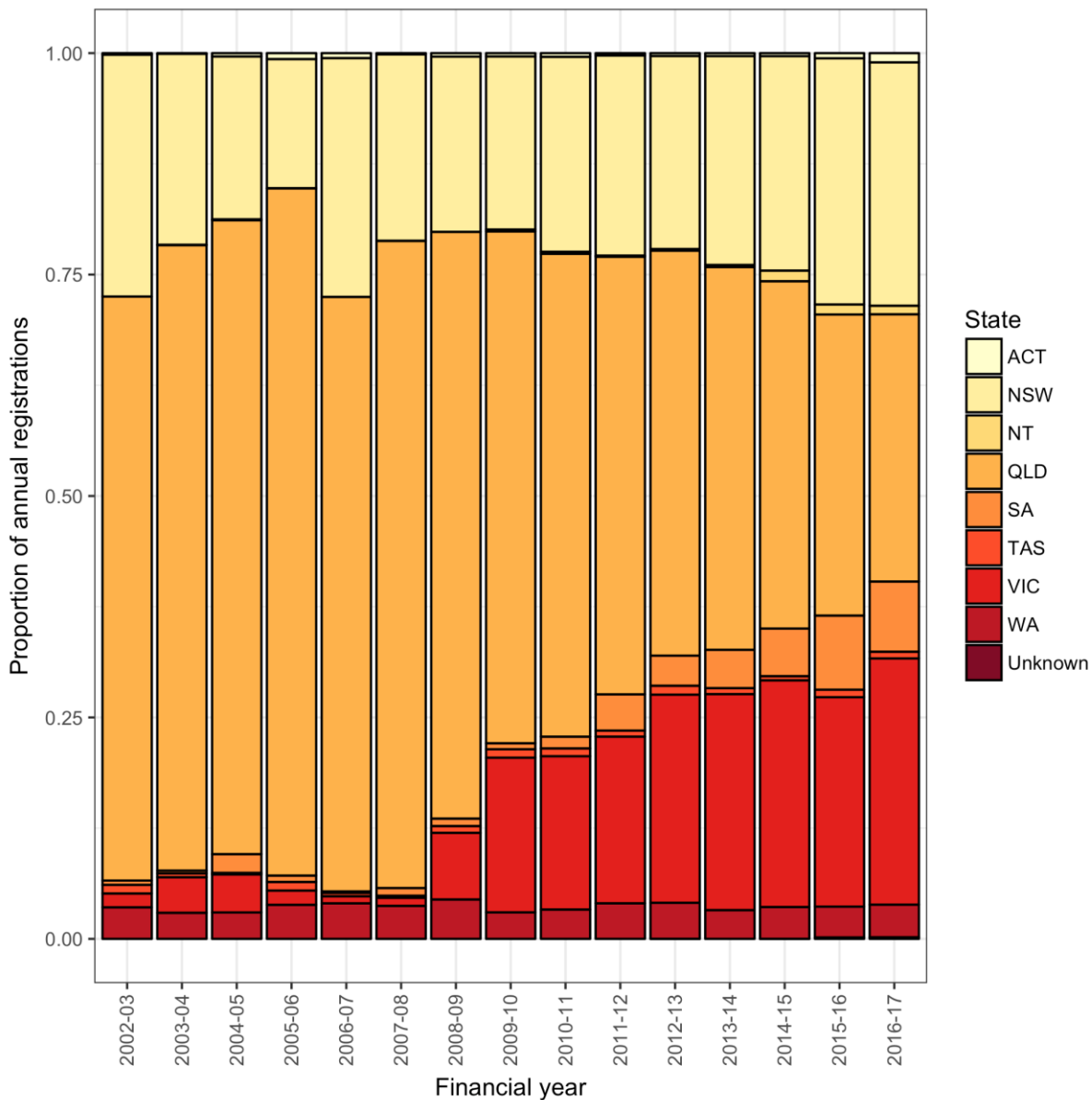


Figure 3 Proportion of new Q fever registrations by state and financial year

5.1.3 Place of work of Registrants

Figure 4 shows the proportions of registrations by work group category. When registrants fill in the *Personal Details and Consent Form*, they are asked to indicate their type of work by choosing from one of four categories:

1. work at a processing plant
2. visitor or contractor to a processing plant (e.g. laundry, plumber, electrician, caterer)
3. work with animals, but not at a processing plant (e.g. farmer, saleyard worker, transport operator, veterinarian)
4. other.

Overall, more than three quarters of registrants either work at, or regularly visit, processing plants.

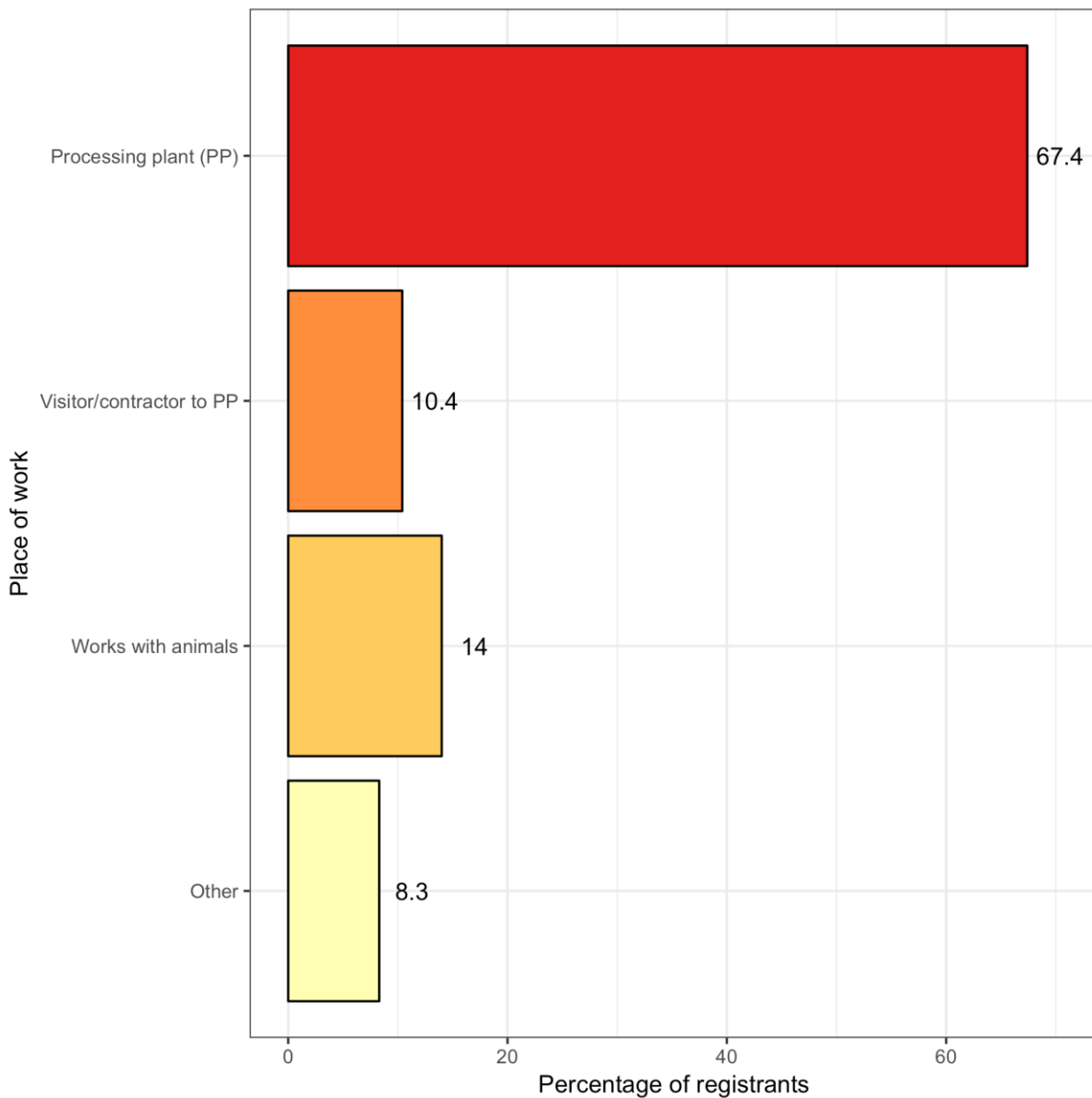


Figure 4 Proportion of Q fever registrations by place of work, 2002- 28 June 2017

5.1.4 Method of registration

Figure 5 shows new registrations by year and method of data entry from 2010 to June 28, 2017. This figure shows that the workload of the Register staff in entering new registrations was similar in 2016-17 to that in 2015-16, despite a slight decrease in overall number of new registrations.

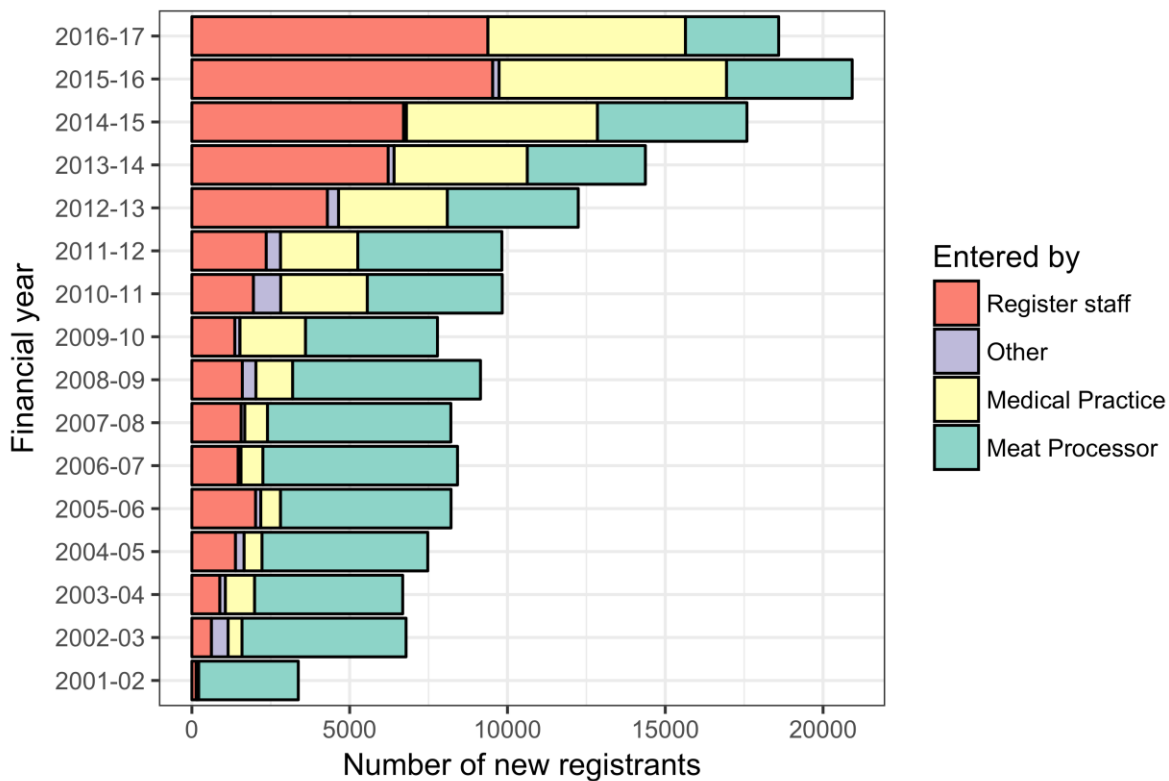


Figure 5 Q fever registrations by financial year and method of initial data entry.

5.1.5 Register Help Line

The Register provides support by responding to queries received by email, fax or phone call. The Register help-line is staffed from 8:30 am to 5:00 pm during workdays from Monday to Friday.

The Register website also provides a great deal of Q Fever information of interest to patients, employers and health practitioners.

Register staff record help-line activity as a measure of workload and community engagement. Phone calls are recorded as short calls if they are resolved in the space of a single call (while the caller is on the line) and as long calls if they require additional work and one or more follow-up calls.

illustrates the help-line activities from July 2010 to June 28 2017. The disproportionate increase in help-line interactions in the third quarter of 2015 is attributable to the Landline television program screened on 12 July 2015, which described severe impacts of Q Fever in a small number of Australians.

Note that Register staff handle, on average, at least 40 telephone calls per day.

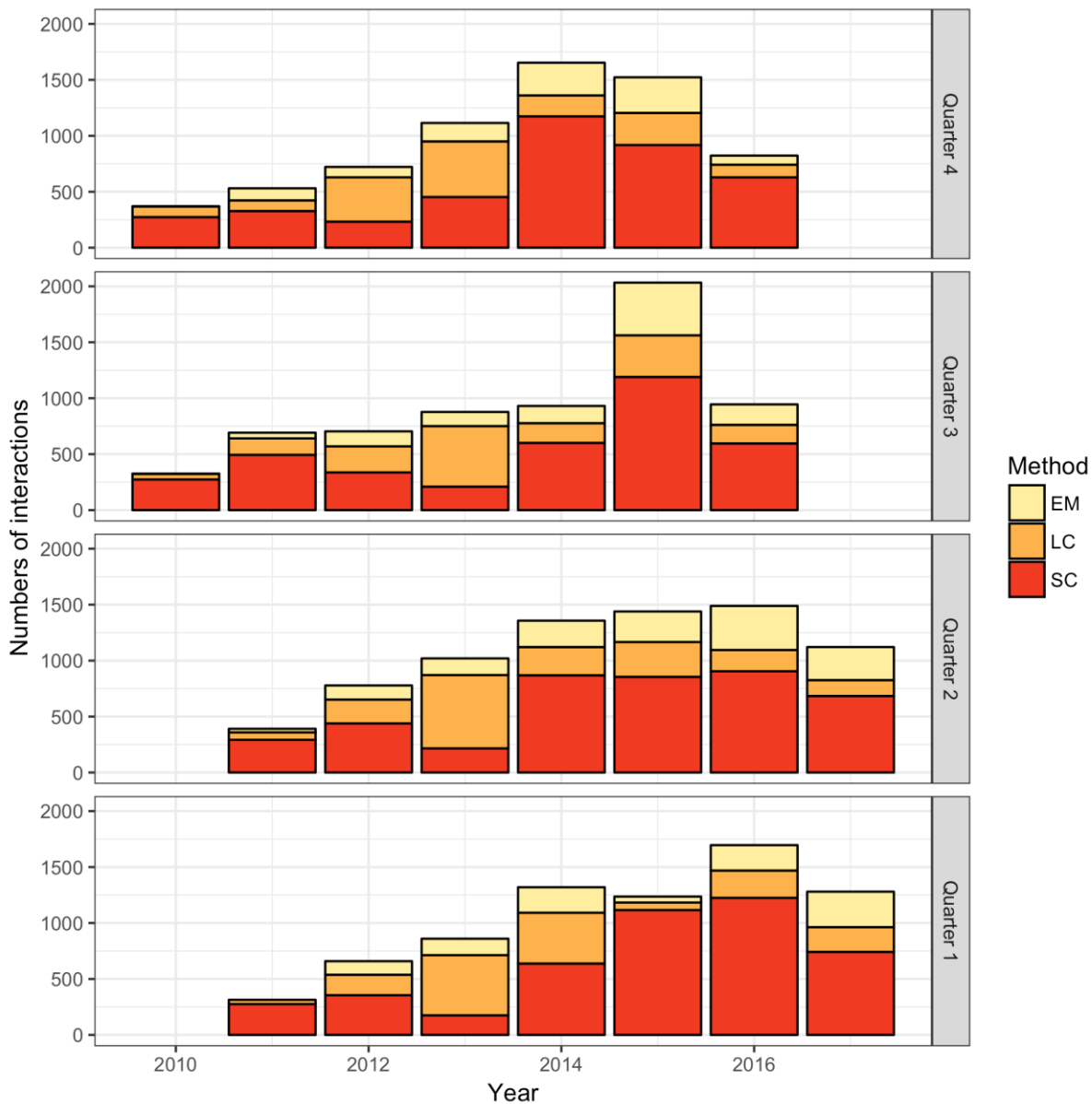


Figure 6 Help line activity as measured by numbers of interactions conducted by Q Fever Register staff, by year, quarter and method, from July 2010 to 28 June 2017. EM: email, LC: long call, SC: short call

5.1.6 Quality Assurance

The Register has data management and quality assurance processes in place to ensure data integrity and quality are maintained to very high standards.

The website and underlying database are backed up in a secure, encrypted process designed to meet or exceed commercial requirements for data security, using short-term backups in multiple Amazon data centres and a single long-term archive backup for long term security.

There are multiple levels of quality assurance for the Register.

The first is in the procedures that form part of the routine operating procedures for the Register.

Register staff review and reconcile all paperwork and Register records before a Q Fever card can be issued.

In addition to rigorous operating procedures, the Register completes a 6-monthly audit of records. The audit involves random selection of 500 records from the Register database and checking information on the scanned PDF records against the electronic information stored in the database.

Any errors are checked and where appropriate corrected. Error rates range from 1 to 2% and errors are typically associated with non-critical information such as address details, spelling of names, post code errors. It is important to note that address errors are expected because people change address from time to time and the Register commonly receives phone calls from people updating their address details. In these situations, the current address stored electronically in the Register will not be the same as the original address recorded on the scanned paper records.

The most recent audit – June 2017 – reported less than 2% errors, with none having any adverse impact on any individual's Q Fever status or risk.

5.1.7 Ensuring that Register operations meet privacy principles

Since inception the Register has been designed and operated to comply with the Australian Privacy Principles (APPs) in the Commonwealth Privacy Act 1988.

A detailed privacy policy is available on the Register website.

The administrative office of the Register is securely locked at all times when not attended, and is in a building equipped with full external locks and burglar alarms.

Access to the register on-line is controlled by password. Passwords are only issued to registered users once appropriate forms have been submitted and checked and after Register staff have spoken to the user to check their identity and the identity of the organisation they work for. The importance of password security is stressed to all users during training. All registered users can only access those parts of the Register that are necessary for the functions they are performing.

All register data passed over the internet during web sessions is securely encrypted using SSL to avoid inadvertent access to information by any third party.

For any telephone enquiries regarding personal information on the register, individuals are required to identify themselves using name, date of birth and secret question to confirm their identity. No information on immune status can be given to a third person without the direct and explicit consent of the individual involved.

The Register is now maintained as a paperless service and all paper forms are scanned and stored digitally in PDF format. All paper forms are then shredded on site by a reputable commercial secure waste destruction company. No paper records associated with patient identification or Q Fever test/vaccination procedures are retained by the Register and these paper records are never allowed to leave the Register premises except to be shredded.

The Register has a procedure for responding to and managing complaints. In the sixteen years of Register operation staff have responded to a very large number of queries and have not received any formal complaints about how personal information has been managed by the Register.

5.1.8 Use of Register data for research purposes

During 2016-17, AMPC approved the use of Register data for use in research proposed by the University of Queensland to assess aspects of Q Fever notifications and vaccinations in Australia. A copy of the letter of request is appended.

5.2 Other activities

5.2.1 Preparation of transition strategy

Documents outlining the requirements for operation of the Register by (another) service provider were prepared.

5.2.2 Demographic analysis

A demographic analysis of existing registration data was conducted. A focus was to describe which entities were conducting Register work for whom (which type of persons). These analyses show that the proportion of registrations entered by meat processor organisations is declining steadily over time (currently around 20%), with Register staff entering half of all registrations, and medical practices entering the remainder (around 30%). Of persons who describe themselves as working at meat processing works, less than a third are registered by meat processor organisations directly.

5.2.3 External document upload feature and attachment of existing documents to the register

The secure storage of scanned registration documents has been greatly enhanced by attaching them to the Register itself, instead of the previous practice of storing them on a Network-Associated Storage Device located (albeit securely) in an office.

The ability to attach registration documents directly to the Register is now available to external Users (meat processor organisations, medical practices) who may wish to transmit documents this way rather than use mail, fax, or email options.

5.2.4 Preparation of proposal for new funding model

A new funding model for Register operation has been developed, and preliminary consultation with stakeholders has been conducted. The model is based on the concept of privatisation of Register operation, with funding contributed by stakeholder groups in proportion to the registration of their representatives. However, the need for and acceptance of such a model in the longer term is not likely. Feedback from government representatives indicated that the future of Q Fever immune status and vaccination records lies with the Australian Immunisation Register. This makes acceptance, progression and adoption of the privatisation model in the short- to medium-term much less certain, although the short-term issues with funding the Register remain.

6.0 DISCUSSION

This year has been quite as busy as the previous year for Register staff in terms of operating activity, despite the slight overall decrease in numbers of new registrations, because the number handled by Register staff was the same.

Although significant progress has been made towards understanding possible options for future Register operation that differ from 'business as usual', the short- to medium-term problems of funding remain. In addition, the long-term solution (incorporation of Q fever immune status and vaccination information in the Australian Immunisation Register) does not provide the existing level of service to industry and industry stakeholders, as it will not provide a help line, and will not have access to any historical data contained in either the Australian Q Fever Register or the legacy Victorian database, which ceased operation in 2008. We note that lack of access to this historical information could put individuals at risk of revaccination which can have serious adverse health effects.

7.0 CONCLUSIONS/RECOMMENDATIONS

That AMPC notes:

1. that 18,594 individuals were added to the Register between 1 July 2016 and 28 June 2017
2. the demonstrated use of Register data to support research efforts in 2016-17
3. that decisions concerning the short- to medium-term operating model for the Register are required
4. that long-term inclusion of Q Fever immune status and vaccination information in the Australian Immunisation Register will not (cannot) include any access to historical and legacy information.

8.0 APPENDICES

8.1 Appendix 1 Research request from the University of Queensland

Provided separately - QFeverDataRequestletter_3August2016.pdf