



## Owner information sheet

### What is the Canine Cruciate Registry (CCR)?

The CCR is a database of information about cruciate surgery in dogs from across the UK. The aim is to improve the outcomes of cruciate surgery performed on dogs. Patient outcomes will be evaluated using feedback from owner questionnaires and by monitoring any complications that might arise. The information you provide will be very useful in helping us to identify which procedures work best and what factors may be associated with good and bad outcomes.

### What does it involve?

If your dog has been diagnosed with a cruciate rupture, your vet will ask if you wish to be involved with the cruciate registry project. Once your vet has submitted your details, you will receive an email asking you to register and fill in a questionnaire about your dog's lameness. When your dog has had surgery, your vet will submit data about the surgical procedure performed. You will then receive regular emails asking about how your dog is doing. You will be asked to complete the same short questionnaires and asked to report any complications. The registry is free to use for both owners and veterinary surgeons.

### How does this help my dog?

By taking part, each time you complete a follow-up questionnaire the vet who operated on your dog will be able to see how your dog is doing in comparison to other dogs who received the same operation. These scores may indicate that your dog is either doing as well as to be expected or may suggest that a re-examination is needed. As well as helping your own dog, your participation will help all dogs needing cruciate surgery in the future by helping us to know which techniques give the best outcomes and have the fewest complications.

**If you have any worries about how your dog is doing, you should still contact your own vet, or the vet who performed the surgery, directly.**

### Who runs the CCR?

The Canine Cruciate Registry is funded by RCVS Knowledge, who are dedicated to advancing the quality of veterinary care for the benefit of animals, the public, and society. They are the charity partner of the RCVS (Royal College of Veterinary Surgeons). The registry and online portals are managed on a day-to-day basis by Amplitude Clinical Outcomes, a global leader in online registry software.

### **Do I need to take part?**

You do not need to take part, but we hope we have shown how your participation will help your dog and other dogs. If you would like to participate, we need your consent. Your decision to take part, or not, will not affect the treatment your dog receives in any way. You are free to withdraw your consent from the registry at any time, without any detriment to the care of your dog(s) either now or in the future. Once you withdraw your consent only anonymised data will remain.

### **How do you obtain my consent?**

If you wish to participate in the Canine Cruciate Registry, your veterinary surgeon or another member of the practice team will enrol you through your email address. You will receive an email which contains a link that takes you to the registration process, where you will provide your explicit consent electronically.

Alternatively, if your vet is participating in the CCR, you can register directly at <https://caninecruciateregistry.org/take-part/>.

### **What personal data do you collect?**

With your consent, we collect the following personal information and process it securely under Article 6 of the General Data Protection Regulations and UK Data Protection Act 2018.

- Your email address
- Your name
- Personal security information, in the form of a question to secure your account.

### **Can anyone else access my data?**

RCVS Knowledge can access your data to administer the registry and provide feedback to your veterinary surgeon. Amplitude can access your data to administer the registry. Anonymised data may be made available to other organisations, for example, academic establishments for research purposes. Each request to access data will be considered on its merits by the registry steering group. No other organisation will be able to access your identifiable personal information apart from your veterinary surgeon and other members of the practice team involved in your dog's healthcare. The joint data controllers are RCVS Knowledge Canine Cruciate Registry and your veterinary surgeon. The data processor is Amplitude Clinical Outcomes, our IT partner. To view the levels of data security on the platform visit <https://amplitude-clinical.com/information-governance-information/>

### **What happens to my data?**

We will use personal data solely to contact you to assess the progress of your dog. The registry will use the data collected from questionnaires to analyse the care and outcomes across a large number of dogs who have had surgery. Submitted animal data will be anonymised to ensure you as an individual cannot be identified by third parties. Your vet will have access to the data about your dog to evaluate the treatments they perform and assess clinical progress.

### How long will you keep my data?

Your personal data will be stored for the length of time you wish to remain part of the register. At your request, your personal data can be removed from the register at any time. However, to ensure consistency for our results, we will keep all anonymised animal-related data indefinitely.

### How long do I need to take part?

It would be great to hear from you about your dog and their cruciate surgery for as long as possible after the operation. The more information we get, the better conclusions we can make from it. Most studies only show information about the first few years after an operation so if you keep telling us information for as long as possible it will be really useful.

If you no longer wish to complete questionnaires, you no longer own the dog, or sadly your dog passes away, please let us know, and we will stop contacting you. You can also do this directly from any follow-up emails we send you.

### Can I withdraw consent?

You can withdraw consent at any time without explanation. Results up to the period of withdrawal will be used in an anonymised format.

### How can I find out more information?

For more information, please visit our website [www.caninecruciateregistry.org](http://www.caninecruciateregistry.org)

RCVS Knowledge's Privacy Policy is available at [www.rcvsknowledge.org/rcvs-knowledge-privacy-policy/](http://www.rcvsknowledge.org/rcvs-knowledge-privacy-policy/)

**If at any point you have any clinical concerns about your dog you should contact your veterinary surgeon directly, not via the Canine Cruciate Registry.**

### Any Questions?

If you have any questions regarding the platform itself, including login and password details, your profile on the platform and any other technical questions, please contact Amplitude Clinical Outcomes: [customer.support@amplitude-clinical.com](mailto:customer.support@amplitude-clinical.com)

If you have any questions related to Canine Cruciate Registry project, please contact: [ebvm@rcvsknowledge.org](mailto:ebvm@rcvsknowledge.org). We respond to all emails within five working days.

Last updated: 22/02/2021



### Consultation

Following patient assessment, a diagnosis of cranial cruciate ligament rupture is made by the veterinary surgeon. If the veterinary surgeon and the patient owner decide that surgery is needed, the owner is asked by the veterinary surgeon or a member of the practice team to participate in the registry.



### Enrolment

If the owner agrees, the surgeon or other member of the practice team adds the patient to the Canine Cruciate Registry with the owner's email address.



### Registration

The system generates an email which is sent to the owner's email address. It includes a link to the registry. The owner clicks on the link, completes the registration process, and provides consent electronically. Registration can also be done directly through the website.



### Assessment

The owner answers a set of questions electronically to provide the patient's baseline outcome measures on their computer, tablet, or smartphone.



### Follow-up

The owner receives regular requests by email to complete follow-up questionnaires, for as many years as possible. The owner can also report any complications that occur. As well as helping your own patient, your participation will help all dogs needing cruciate surgery in the future by helping us to know which techniques and implants give the best outcomes and have the fewest complications.



### Surgical report form

Either before or at the time of surgery the surgeon should complete the initial veterinary assessment. Once surgery has been performed, the surgeon or other member of the practice team will log into the registry and complete the surgical report form.



### Data

Surgeons can review their own data in real time for personal clinical audit purposes, and will be able to make comparisons with anonymised data across the registry. Reports can be generated automatically or manually.



### Reporting results

On an annual basis the Canine Cruciate Registry will compile anonymised results to report on the data collected from the entire registry. These reports will be available via [www.caninecruciateregistry.org](http://www.caninecruciateregistry.org)