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Developing and implementing a Danish disease registration system for companion animals

A report on past experience, and the opportunities and challenges ahead

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July 2015

Foreword

Small animal vets (throughout this report we use the simple term ‘vet’ to avoid having to choose between the British expression ‘veterinary surgeon’ and the American ‘veterinarian’) play a central role in management of the health and welfare of Danish companion animals. They diagnose and treat dogs and cats on a regular basis, and they record their diagnoses and treatments in individual databases. A large number of records are produced, but they are not combined and shared, and therefore a huge opportunity to know more about, and potentially improve, health and welfare in Danish dogs and cats is being missed. The present report aims to lay foundations on which this failure can be rectified.

We would like to thank a number of individuals and organisations without whose support we would not have been able to prepare the report: the Danish Center for Animal Welfare (Videncenter for Dyrevelfærd, VID), our working group members Björn Forkman, Merete Fredholm, Merete Holst Nissen, Helle Friis Prochowsky, Vibeke Knudsen, Brenda Bonnett, Dan O’Neill and James Serpell; collaborators within the Danish Veterinary Association, Karina Ryborg and Niels Filtenborg-Barnkop, and those who contributed information in interviews, Jacob Kjær Larsen, Brenda Bonnett, Pekka Olson, Sonja Karaoglan, Dan O’Neill, Hans-Petter Bugge, Stein Istre Thoresen, Gudbrand Vatn, Maria Lundvall, Mette Uldahl, Helle Wied, Niels Østergaard, Ole Abildgaard, Ida Tingman Møller, and Louise Bundgaard. Special thanks are due to Brenda Bonnett, Dan O’Neill, Stein Istre, Jacob Kjær Larsen, Niels Østergaard, Ida Tingman Møller, Helle Friis Prochowsky, Vibeke Knudsen, Susanne Krarup Larsen and Sonja Karaoglan for reading and commenting on an earlier draft of the report.

This report will only be of value if its findings and recommendations are taken up by those responsible for setting up, running and delivering input to a Danish disease registry for companion animals. We therefore very much hope that the Danish Veterinary Association, the Danish food and veterinary authorities, the University of Copenhagen and last, but not least, the many Danish vets working in small animal practice will collaborate to get the project off the ground. This would in the long run benefit companion animals, their owners, vets themselves, and those doing research in companion animal health and welfare.

Frederiksberg, 1 July 2015

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List of abbreviations

AAHA	American Animal Hospital Association
DCAW	Danish Center for Animal Welfare
EBVM	Evidence Based Veterinary Medicine
IHTSDO	International Health Terminology Standards Development Organisation
PetCHAMP	Pet Computerized Health And Management Program
PMS	Practice Management System
RVC	Royal Veterinary College
SDF	Specialpraktiserende Dyrlægers Forening
SNOMED – CT	Systematized Nomenclature of Medicine – Clinical Terms
VetCompass	Veterinary Companion Animal Surveillance System
VID	Videncenter for Dyrevelfærd

Introduction

In 2010 a working group was appointed by the Danish Ministry of Justice to investigate animal breeding and its welfare-related impact on the animals. Included in the remit for the group was an evaluation of breeding and breeding-related welfare impacts on dogs and cats. Two breeding-related welfare problems for purebred dogs and cats were identified by the working group: problems related to breeding for extreme conformation, and problems with breeding-related hereditary diseases. The final report from the group in 2013 made a number of recommendations on how to deal with these problems (Fødevareministeriet, 2013). One of the recommendations was that data from small animal clinics should be made available to enable an estimate of the true prevalence of hereditary diseases to be made, and to evaluate the effects of possible breeding-related initiatives in Danish purebred dogs and cats.

In 2014 a research project with the title 'Breeding for improved welfare in purebred dogs' was granted money from the Danish Centre for Animal Welfare (DCAW). The overall aim of this project is to facilitate the prevention of welfare problems related to the breeding of dogs. Following up on the above-mentioned recommendation, one of the objectives in the DCAW-funded research project is to investigate the possibility of establishing a disease registration system that can be used with the practice management systems used in Danish small animal clinics. It is the outcome of this part of the project that is presented in this report.

A national disease registration system would not only be beneficial for research and work on the importance of hereditary factors for the health and welfare of purebred dogs and cats. It would also potentially improve our knowledge of many other kinds of disease in dogs and cats, and it would be highly relevant in the surveillance of other welfare problems – for example, problems related to obesity and undesirable behaviour.

Such a system would, of course, be useful to the veterinary profession in a number of ways. For example, in Evidence Based Veterinary Medicine (EBVM), evidence for the best possible treatment, based on data from a population of animals, is applied to the individual patient (Faunt et al., 2007; Slater, 2010; Jones-Diette, 2014). Standardized coding terms in an electronic practice management system offer an opportunity to practice EBVM by providing the veterinarian with information about the most common conditions and treatment outcomes. The collation of such registrations from several veterinary practices in a national disease registry will potentially contribute even further to EVBM by providing data for practice-based research that will improve

our general understanding of veterinary medicine and optimal clinical decision-making (Faunt et al., 2007; Jones-Diette, 2014).

For the Danish authorities a national disease registry for companion animals would be very advantageous in situations where overviews of the prevalence of different diseases are requested. A continued political focus on companion animal welfare is likely to generate more requests of this type.

Purpose of the report

The purpose of the present report is to investigate and describe opportunities and challenges in the development and implementation of a Danish disease registration system for companion animals. The ambition is to produce a report that can be used by future contributors in developing and establishing this system.

The report consequently has the following objectives:

- To discuss the various purposes that a Danish disease registry may serve, and present the choices that have to be made given the prioritization of these purposes
- To identify the technical possibilities and personal incentives for vets which may favour the development and implementation of a national disease registration system
- To identify important issues that need to be addressed to ensure successful development and implementation of a national disease registration system
- To suggest possible ways of moving forward to deal with these issues

Method

The report will be based on information on previous initiatives in Denmark and on current international initiatives to develop and implement disease registration systems for companion animals. Information on similar initiatives for horses in Denmark will also be presented, as will information on the interests of, and requests made by, various stakeholders. In addition, relevant

literature on disease registration systems, data extraction from practice management systems, epidemiological research and evidence-based veterinary medicine will be included.

Information for this report was collected mainly through interviews with relevant researchers and stakeholders. The following people have provided information for the report:

- Jacob Kjær Larsen, DVM, a practicing vet and one of the developers of a similar previous initiative, SDF statistics.
- Brenda Bonnett, DVM, PhD, epidemiologist and author of numerous publications on epidemiological studies of companion animal diseases based on data from the insurance company Agria; currently CEO, the International Partnership for Dogs.
- Pekka Olson, DVM, PhD, h. c. Manager Veterinary Strategies Agria Animal, involved in the development of one of the most widely used diagnostic coding systems in Sweden as well as in cooperative work between Sweden and Norway on a shared Swedish/Norwegian diagnostic registry for companion animals.
- Agria representative Sonja Karaoglan.
- Dan O'Neill, DVM, companion animal epidemiologist at RVC and developer of VetCompass, an international disease registration system based in the UK.
- Representatives from a group working with the development of a shared Swedish-Norwegian diagnostic registry for companion animals: Hans-Petter Bugge, secretary general in the Norwegian Veterinary Association; Stein Istre Thoresen, professor at the Norwegian School of Veterinary Science; Gudbrand Vatn, manager at Dyreidentitet A/S; Maria Lundvall, secretary general in Svensk Djursjukvård; and Pekka Olson.
- Mette Uldahl, DVM, a practicing vet at Vejle Hestepraksis and involved in recent efforts to establish a disease registry for horses in Denmark.
- Representatives from the practice management system (PMS) providers Novasoft (Helle Wied and Niels Østergaard), Skyvets (John Pedersen) and Novax Vet (Ole Abildgaard).
- Representatives from the Danish Veterinary Association (Ida Tingman Møller, DVM and Louise Bundgaard, DVM).

The findings

Collectively, the interviews suggest that three general criteria will need to be met if a disease register is to work in accordance with the objectives listed above:

1. The system must be user friendly and should not require vets to do any extra work without direct benefit to themselves.
2. The system must fulfil legal requirements, not least by observing good data protection. Vets and the owners of companion animals must also have confidence in the high level of data protection.
3. The system must give added value to the vets, and provide benefits for research and for companion animals.

To satisfy these three criteria, we have identified five key questions that need to be addressed:

1. What purposes should the disease registry fulfil?
2. How are diseases and treatments best recorded by the vet?
3. How are data from vet's practice management system reported to a central registry, and what information should be reported?
4. How can vets be encouraged and motivated to report data to a central registry?
5. How should a national disease registry be managed and financed?

1. What purposes should the disease registry fulfil?

It was emphasized by many of the interviewees, and it is also stressed in the literature (Houe et al., 2011), that it is extremely important that the purpose and use of a diagnostic registry is considered carefully before it is designed and developed.

One may dream of a system that is, at the same time, easy to use, has a wide uptake and provides detailed and accurate information in every field of canine and feline health. However, this is not a realistic dream. In reality there will be a trade-off between, on the one hand, simplicity and wide uptake, and on the other, precision, detail and accuracy.

Registration of the occurrence of disease in companion animals is vital, whether this is done by registering diagnostic codes or by searching in the free text of veterinary records as described below. But a registry can either collect data about all diseases in companion animals or focus on specific diseases. Therefore an alternative to one national disease registry for companion animals is

to have several disease registries, each of which registers more specific disease information (like the existing cancer registry). The vets would then have to code only for the limited number of diagnoses used in these registries. If patient and veterinary clinic ID were reported to such registries, it would be possible to link different disease registries as well as the veterinary PMSs. So a choice will have to be made, depending on the purpose at hand, between one joint registry for a wide range of companion animal diseases or a network of more specialized registries; and the choice may, among other things, be determined by whether one is interested in the big picture or the development in the various branches of specialized veterinary medicine. In many cases a general system, trying to 'capture everything' will be insufficient when it comes to answering specific research questions about animal disease. Equally, a patchwork of specialized registries may not be very good at providing the big picture.

Also there may be ambitions to use the system not only to register the prevalence of diseases but also to find out what vets do to prevent and treat diseases. And there may be an interest in issues that are not directly linked to occurrence of diseases, such as general health parameters (e.g. body condition scores) and the euthanasia of unwanted companion animals.

So, depending on its purpose, a disease registry should collect information about things other than diagnosis. Information on veterinary treatments and procedures, the amounts of medication given, the relative weight of the animal (degree of obesity) and other matters can be very useful for research on companion animal disease and its risk factors, as well as for EBVM. However, the collection of such information should not compromise the criteria of user-friendliness and minimal extra work for the vets. Moreover, as has been pointed out, systems that are too general often do not provide answers to more specific questions.

Once it has been decided what the system is to be used for, the development and design process can start. In this process, purposes, goals and desired levels of detail, should be balanced against practical possibilities and limitations.

2. How are diseases and treatments best recorded by the vet?

It was evident in all of our interviews that a standardized method of registering diagnoses and possibly also procedures, treatments, and presenting signs, as well as species and breed, in the veterinary clinic is imperative if the registrations are to be used at population level, either by the veterinary clinic or by researchers. The literature supports the importance of standardized veterinary nomenclature in practice-based research and disease surveillance (Sestoft, 2010; Santamaria and

Zimmerman, 2011; Jones-Diette, 2014). However, the most effective way of standardizing veterinary nomenclature is not as obvious, and we have identified several nomenclatural systems. Three of these will be described here.

The Swedish diagnostic code system

This system was developed in 1992/1993. Pekka Olson was part of the team which developed it. Agria, who funded the development, had an interest in the vets using standardized diagnoses to make it easier to handle insurance refund cases; and along with other epidemiologists, Pekka Olson, who was at that time working at the Swedish University of Agricultural Sciences (SLU), had an interest in improving data for epidemiological studies. The work resulted in a book containing all the diagnostic codes now used by most PMSs in Sweden. The system has a hierarchical structure, and this should enable the vet to choose the level of diagnosis that is possible in a given situation.

The system is owned by Svensk Djursjukvård (previously Svensk Djursjukhusföreningen), a professional organization for veterinary clinics, and is currently undergoing a major modification. In the new version, which is being developed cooperatively by Sweden and Norway, the diagnostic coding system is part of a larger system called Pyramidion and is owned by Svensk Djursjukvård and the Norwegian registry for dog ID numbers, Dyreidentitet. The number of diagnostic codes here is reduced from more than 8500 scientific codes in the existing Swedish system to approximately 4000 such codes in Pyramidion. Topographical information is placed in a separate list, and the system permits the addition or alternation of diagnostic codes over time, and allows synonyms to be added to the scientific diagnoses (that are based on Latin/English-Latin/country-language terminology).

As already mentioned, the system has a hierarchical structure, but unlike in the earlier versions, it is no longer necessary for the vets to go through the hierarchy or remember a specific disease code when using the system. Instead they can use free-text input to look up diseases.

For Denmark to use the Pyramidion, the approximately 4000 scientific codes would have to be translated or verified. In addition Danish synonyms could be added in an adjustment to the system to make it user-friendly for Danish vets. In its standard form, this system does not register veterinary procedures (e.g. neutering, vaccination) or treatments (e.g. medication), but such registrations can be added to the system.

VeNom codes

This system was initially developed in 2004 at the Royal Veterinary College (RVC) in London. Most of the other UK veterinary schools, and the veterinary charity People's Dispensary for Sick Animals (PDSA), have contributed to the development as well; and the codes are now maintained by a multi-institution group, VeNom Coding Group (www.venomcoding.org).

Today the VeNom codes are used by many PMS providers in the UK. Insurance companies on the UK market, who mainly use the Swedish diagnostic code system at present, are considering using the VeNom codes. The VeNom codes can be linked to the Systematized Nomenclature of Medicine – Clinical Terms (SNOMED - CT), but they are less extensive than the latter and oriented towards veterinary medicine. The VeNom codes comprise mainly diagnoses (2291), but it also includes species, breed, procedures, diagnostic tests and presenting complaints (i.e. reasons why the owner brought the animal to the vet).

The VeNom codes are open-access and can be consulted by anyone who is interested, but an agreement to use the codes as they are has to be signed before one uses the system. This is to ensure that the list is the same everywhere it is used. Additions and changes to the system can be made by contacting the coding group. The VeNom codes have also been exported to other countries such as Australia, France and Germany.

SNOMED CT/AAHA Diagnostic Terms

SNOMED CT provides what is considered the most comprehensive (human) clinical health care terminology in the world. The International Health Terminology Standards Development Organisation (IHTSDO) that owns and administers SNOMED CT is working to make this system the global language for health terms. In Denmark SNOMED CT is being implemented in the human health care sector. In 2010 the American Animal Hospital Association (AAHA) Diagnostic Terms were developed as a subset of SNOMED CT. These terms are maintained by the Veterinary Terminology Services Laboratory. They are updated twice a year and currently include 5200 terms. As far as we can discover, so far the system has only been used in the US, and we have not consulted with anyone who uses the system.

Important aspects to consider, with these three systems, include the number of diagnostic codes, the degree of hierarchical organization of the system, and the ability to register and code for veterinary procedures like vaccinations or neutering, besides coding for diagnoses.

The Swedish diagnostic code system does not register procedures, and according to Pekka Olson it is neither possible nor sensible to try to include procedures or treatments in the list of diagnostic codes, because the ways in which vets treat their patients are idiosyncratic and would therefore be very complicated to code for. Olson does not, however, see a problem in trying to make a separate list of procedure/treatment codes that can be added to the diagnostic code system, rather like the list of topographical information in the new version of the Swedish system.

Procedures/treatments are mostly registered during billing anyway, and the vets can then search their own systems if they want information about the number of procedures/treatments of a certain kind. It may be possible, through a link to the billing system, to import information about procedures/treatments into the system without extra work for the vet. Such information could be very valuable from a research point of view as well as in the practice of EVBM. Therefore the possibility of including treatments, or at least a certain set of treatments, in a national disease registry, seems important.

With regard to the number of diagnostic codes, all three of the systems described have a very high level of detail. According to Jacob Kjær Larsen, a previous attempt to make a diagnostic registry was probably too ambitious in including a diagnosis list, a procedure list and a medication list, besides information about the patient. It was based on a translation of the American Pet Computerized Health And Management Program (PetCHAMP) with less than 1000 diagnoses. In a study of disease prevalence in dogs attending primary-care vets, 430 distinct diagnoses were used, with 3884 dogs seen in 89 clinics during a period of three and a half years (O'Neill et al., 2014).

According to Brenda Bonnett, Swedish vets use approximately 4900 of the 8500 codes in the Swedish diagnostic code system when they diagnose dogs, but they use fewer diagnoses for cats (approximately 2400). The benefit of having a lot of diagnoses is that the level of detail rises very high. From a research point of view this is preferable, as long as the diagnoses are valid. The disadvantage of having a large number of diagnoses in a system is that the system then becomes more complicated to use. Also the validity of the data collected deteriorates, as vets facing a large number of codes have a tendency to cut corners and use the diagnostic codes they know instead of searching for a more correct diagnosis.

A similar validity problem is that vets tend, in any case, to report diagnoses they feel confident about rather than the more difficult diagnoses. Therefore there may be good reasons in a research

setting to focus on rather broad categories of diagnosis. This is possible in a hierarchical system, however fine-grained it is in its totality. Most of the interviewees agreed that it is important not to make the system too ambitious. However, Dan O'Neill believed that if things are simplified too much, it becomes difficult to guarantee that data collected are suitable for research purposes. Rather than restricting the list of coding terms for vets, the RVC is working on a VetCompass web-based coding system that will make coding easier and encourage higher levels of clinical coding by practicing vets.

Both the Swedish diagnostic code system and VeNom are hierarchical. For example, the vet first chooses an organ system, then a level of that organ system (e.g. upper versus lower airways), then the kind of disease process (e.g. congenital, metabolic, toxic, traumatic, etc.), and then a specific diagnosis. In theory this enables the vet to make a diagnosis at the level that he/she can with the given patient at a given point in the diagnostic process *(*remembering that many conditions are chronic, or not fully/accurately diagnosed until the patient has been seen repeatedly*).*

In practice however, according to DVM Mette Uldahl, who works with similar systems for horses, the hierarchical systems are very difficult and laborious to use in a busy working environment. Often the vet will end up choosing a rough and ready diagnosis to get on in the PMS, with serious consequences for the validity of data collected in such a system. Mette Uldahl has worked for several years on a common diagnostic code system for vets sharing night and weekend duties, but has ended up abandoning the planned system as a result of the inadequacy of the software used.

According to the developers of the Swedish/Norwegian diagnostic coding system, the problem lies not in the hierarchical structure of the system, but in how the vet is presented with the possibilities the system offers at the user interface of the PMS. It should, for example, be possible for the vet to search a given diagnosis using free text and then be presented with possible matches with the search term. The way the new Swedish/Norwegian system is built, the vet will also be presented with possible diagnoses located either at a less detailed level of the hierarchy (in cases where the vet is actually not able to make the diagnosis with certainty at the given level) or at a more detailed level (in cases where the vet can make an even more detailed diagnosis).

One alternative to hierarchical arranged diagnostic codes is to use diagnostic codes that are organized more stochastically. However, according to the developers of the new version of the

Swedish/Norwegian diagnostic coding system, such a system will be no less complicated for vets to use.

A third possibility is that the vets, as many do today, should write their diagnoses in the free text of the PMS together with notes and other findings. Researchers can utilize such information if they are able to extract the diagnoses from the free text of the PMSs. Dan O'Neill is currently working with such a method, and similar methods have been investigated (Jones-Diette, 2014). Given that very few vets actually use diagnostic coding – in the UK on average 7% according to Dan O'Neill, and 6% according to a study made by Jones-Diette (2014) – and given also that there is often little agreement between coded information and the free text within the same record (Stein et al., 2000), extraction of information from free text does seem an attractive solution.

However, whereas diagnostic coding appears to be very strenuous for vets to use, data extraction from free text is still in its first stages, and needless to say it appears to require a lot of work for the people collecting the disease data. Moreover, the developers of Pyramidion argue that free-text searching is better suited to the English language, since in the Scandinavian languages diseases have a lot of synonyms. In Sweden the proportion of vets using diagnostic coding is much higher than 6-7% (in many clinics it is close to 100 %), because a lot of the PMSs require the vet to choose a diagnostic code before the bill can be issued. Most PMSs use the Swedish diagnostic code system, and for animals with health care insurance (80% of companion animals in Sweden) the vet has to use a diagnostic code from this system if the insurance company is to reimburse veterinary expenses directly.

A last issue raised by diagnostic coding is the question of how to handle the fact that diagnoses are not fixed. An animal seeing the vet one day might be diagnosed with one condition one day and a different condition a couple of days later when further tests have been done. Without manually looking through the PMSs it is impossible to know whether a diagnosis is the final diagnosis in a course of disease or a provisional one. In some PMSs it is possible to choose 'obs pro diagnoses', and in the new Swedish coding system a 'complication to operation' code can be selected, which at least couples such complications with previous diagnoses. However, it is unavoidable that several diagnoses might be made for a given condition in an animal. Perhaps this is best tackled in the statistical treatment of data collected by a disease registration system.

3. How are data from the vet's practice management system reported to a central registry, and what information should be reported?

Another important step in a national disease registration system is to get data from the PMSs to a central database that stores information about animals and their registered diseases and treatments. On a very practical level, it has to be ensured that vets enter data in their PMSs correctly in order for transformation of data to be possible. The vets have to be motivated to use diagnostic codes for every visit they make (see more on this in the next section), and it is important that information is entered in the correct fields of the PMS, since only some fields will be transferred to the common database.

In one study, for example, the staff at a clinic had entered animal species in the field for the animal's name, which was not extracted to secure anonymity (Jones-Diette, 2014). One way of supporting the correct use of PMSs would be for PMS providers to offer short courses in the use of their specific systems as well as continuing support services. Some PMS providers already offer such services, and where this is so the challenge lies in persuading vets to use these services.

If we are to have a national disease registry collecting data from large numbers of vets, a common database of some form has to be established and managed by someone. Management will be discussed later (see section 5. How should a national disease registry be managed and financed?). For the existing Swedish diagnostic coding system, there is no national disease registry to report to, but for disease cases with health insurance claims, information on diagnoses is stored in the databases of the insurance companies. The insurance company Agria uses this information for research on companion animal health. In Sweden 80% of companion animals have health insurance. However, there are no data repositories or registrations of information on animals that are not insured, cases that are not reported to the insurance company, and veterinary procedures like neutering or vaccinations.

In the new Swedish/Norwegian system, Pyramidion, the aim is that all PMSs will use the same diagnostic coding system. In Norway this system will be offered to PMS providers cost-free, and the system providers, in return, will be obliged to report diagnoses from their clients' PMSs to a national diagnostic registry. In Sweden the PMS providers will pay a fee to use the Pyramidion diagnostic coding system, but they will not be required to report any information back. This way, Sweden will continue without a national disease registry but with a common diagnostic coding system and diagnostic information that is stored with the insurance companies.

In Norway as well as in the UK, where VetCompass is working, PMS providers manage the transfer of information from the vets' PMSs to a collective database storing disease information. The same happens with the collection of veterinary disease registrations in production animals in Denmark. Several PMS providers in Denmark are already working with reporting data to national registries for production animals. According to representatives from one of these PMS providers, the transfer of diagnoses from companion animal PMSs to a national registry should not be a problem and automation of the process should also be possible.

However, Mette Uldahl, who has been working on the development of a disease registry for horses, emphasizes in her interview, that the transfer of relevant and valid information from the vets' PMSs to a collective database is not as straightforward as it sounds. She strongly recommends that the technical details of how to apply disease registrations and transfer data to a national registry are considered carefully.

Extracting information about diseases from the veterinary PMS and transferring it to a national database is unquestionably easiest if the vets are using diagnostic codes rather than writing the diagnoses as free-text notes in the records. In the latter solution there could also be a legal problem if the free text from the PMS has to be exported in full to a central database where disease information is extracted. Vets owns their records, and since there may be sensitive information in the free text, this could place the vet in a dilemma as regards his/her obligations and responsibility.

A decision to base a disease registration system on diagnostic codes would not be without practical complications regarding the reporting of diagnoses to a registry. First of all, if we are to have a registry with a broad set of diagnoses registered, the easiest way forward is for all contributing vets to use the same diagnostic coding system. This system, of course, has to be implemented in all of the PMS software systems to ensure that the vet is not forced to invest in a certain software system. Secondly, it has to be decided how much information should be reported to the registry. If only a smaller set of key diagnoses need to be registered, mapping between different coding systems can be achieved ensuring that the same diagnosis with different codes in different PMSs can be registered identically in a registry. This could be a solution if several smaller/more specific disease registries are favoured over a broader, more all-encompassing disease registry.

Identification of the animal is necessary if counting the same animal twice is to be avoided. Such double counting of the animal and the incident might happen in cases where the animal is treated in

several clinics for the same disease incident (e.g. seeing a primary care vet first and a referral practice afterwards) or in cases where the owner is obtaining second opinions about the disease incident. Identification of the animal is also necessary if the information about diseases is to be compared with other sources of information, such as information from breeding registries in connection with breeding related initiatives to improve health.

Identification of the veterinary clinic should also be registered, according to Dan O'Neill, as clinics differ so much in their degree and type of coding that it needs to be factored into subsequent data analysis of disease diagnoses. Information about treatments and use of medication could be very interesting from a research point of view, but also for stakeholders from the private sector (e.g. medical companies) if these are to be able to utilize the information in a national disease registry.

Animal/veterinary clinic identification and medical information both need to be discussed carefully, since these can be sensitive. To ensure that animal owners and vets will trust the system and feel comfortable about using it, this issue must be dealt with up front. It is, for example, possible to encrypt data on its passage from the vet's PMS to the central database. The encryption should be handled by an institution which has a high level of probity and no personal or commercial interest in ID information, and therefore is trustworthy. Furthermore, procedures for management of the database must be set up to ensure that sensitive data are not normally available to users of the system.

In relation to this, it also has to be decided whether data transfer from the PMSs to a national database should happen automatically or manually, and whether veterinary participation should be voluntary or mandatory. Similarly, it has to be decided whether client participation should be voluntary, and in that case whether it should be based on an 'opt in' or 'opt out' process.

According to all of the people interviewed for this report, veterinary participation has to be voluntary. Although the reliability of data from a national disease registry will increase with the number of veterinary clinics participating, a sufficient subset of clinics that make thorough and reliable registrations for the registry would be better than a larger subset that are not motivated to report to a national registry. One option would be to initially invite ISO-certified veterinary clinics to participate in reporting to a national registry. Since these clinics already are likely to maintain high standards in the registration and reporting of many parameters, the transfer of information

from their PMSs should be fairly straightforward. Today Denmark has 44 ISO-certified veterinary clinics (http://iso-dyrlaegen.dk/find-en-iso-dyrlaege/), and the number is growing.

A system where data are transferred automatically is without doubt the easiest option and would reduce veterinary workload. It could be applied on the basis of voluntary participation by vets. If client consent has to be given for data to be transferred, the vet will be required to tick off a box before finishing his/her record, telling the system whether or not to transfer information from that particular consultation. Alternatively, clients could sign a form when they visit the vet for the first time stating that they agree to allow information about their companion animal's health record be transferred to a national registry.

According to Dan O'Neill, 'opt-out' solutions work best. In this form of consent data are shared unless the client actively declines to share an animal's data. Information on the opt-out must be made freely available at the veterinary practice to ensure that clients are aware of the practice's participation in the data-sharing programme. It is not sufficient that the system complies with Danish data protection legislation. It is also essential that vets, as well as the public, and more specifically companion animal owners, trust the process by which a national disease registry is managed. This will be dealt with in more detail in the next sections.

4. How can vets be encouraged and motivated to report data to a central registry?

Throughout the process of collecting information for this report, two factors, with obvious connections, have been stressed more than any other: the importance of developing a disease registration system that does not create extra work for vets and the need to find the right way of motivating vets to participate. In a survey investigating Danish stakeholders' attitudes to an equine health and disease database, it was found that 90% of vets were willing to supply data for such a database. However, most vets were willing to spend no more than 5 minutes entering a patient's data into a database (Hartig et al., 2013). When we consider that a companion animal consultation is often limited to about 15-20 minutes, it is clear that the practitioner might be willing to spend even less than 5 minutes entering the required data in a PMS.

If a disease registry is to be based on the reporting of diagnostic codes, the first step is to convince vets to use diagnostic coding every time they see or treat an animal in their clinics. As mentioned previously, it appears that the way PMS providers construct the user interface plays a key role in the usability of the diagnostic coding systems. Important points for the vet are: that the right diagnosis

is easy to locate in the system; that it is possible to search for the diagnosis in a free-text field; that it is possible to diagnose at different levels matching the information the vet has at the given point in time; that it is possible to make provisional diagnoses and added diagnoses in cases of longer treatment periods; and that the recording of the diagnostic code feels like part of the general record keeping, not an 'extra step'.

In several countries, including Norway and Sweden, vets are required by law to keep health records for their patients. In Denmark record keeping is not required by law, and is therefore voluntary, unless the veterinary clinic wishes to be ISO-certified, in which case mandatory record keeping and diagnosing are parts of the official requirements. Therefore, as mentioned previously, one way to get started with at national disease registry for companion animals would be to invite ISO-certified clinics to participate.

Working in an insurance company receiving a lot of applications for claims for veterinary expenses, Sonja Karaoglan explained how inadequate records from vets often are. It would be very beneficial for insurance companies if the records were more complete and optimal, and if the vets were to use the same diagnostic coding system as the insurance companies. It would also benefit vets to keep comprehensive records – for example, in cases of client-animal-vet disputes or official complaints.

Moreover, full records of animal visits to the vet would help in legal cases involving sales disputes, as when, for example, owners want to return a defective dog. In view of this, Pekka Olson and Sonja Karaoglan both recommend that veterinary legislation should make record keeping mandatory. Introducing and implementing such a legal requirement, and in particular ensuring its application and quality, is a substantial task. It will require clear and detailed policies, education plans, and so on.

An attractive way to motivate veterinary participation involves the possibility of direct refund of veterinary expenses to the client. In this process the insurance companies require a diagnosis for a refund of the veterinary bill, and the refund procedure is greatly enhanced if the veterinary PMS uses the same diagnostic coding system as the insurance company. In Denmark direct refund is possible in a manual version of this scheme at the moment (the vet faxes or calls the insurance company and receives immediate feedback on the amount that can be refunded). In Sweden, some insurance companies also offer a fully-automated refund system. This makes it possible for vets to

get automatic electronic feedback on the fraction of the bill to be refunded – if necessary, outside normal working hours.

Everyone interviewed agreed that direct refund must be a great motivator for the vets and their clients. The vet is saved the possible problems of clients not being able to pay the bill, and clients are saved the trouble of sending bills to the insurance company and waiting for refunds. The likely preference of many clients for clinics offering direct insurance refunds becomes motivating for the vet as well.

Another possible motivator, mentioned by some of the interviewees, is that veterinary clinics participating in a national disease registry could be given the opportunity to compare their own statistics on diseases, treatments, and so on (depending on the amount of information reported to the registry) with national or regional averages. This form of benchmarking might be useful for clinics making decisions about which areas to improve or invest in.

An outcomes-based argument is that the transfer of information to a national disease registry for companion animals greatly improves our understanding of companion animal diseases, research and development, and treatment protocols. Participating vets would be contributing to, and facilitating, the use of EBVM, not only locally at the clinic but also nationally.

In relation to this, Stein Thoresen from the Norwegian School of Veterinary Medicine pointed out that errors related to the use of diagnostic codes will be compensated for when large numbers of veterinary clinics participate in a national disease registry. Therefore the more vets that participate, the more reliable and valid the conclusions based on data in the registry become. Hartig et al. (2013) found that vets consider it important that data in an equine disease and health database is comprehensive, i.e. that everybody contributes and participates. Moreover, the vets in Hartig's survey reported that meaningful use of such a database is important, leading the authors to conclude that "Ensuring the usefulness of data and informing stakeholders of the results of their data contribution seem to be key tasks for database organizers/administrators" (ibid., p. 90).

If vets are to appreciate the possible impact of their contributions to a disease registry it will be necessary to specify and illustrate the opportunities and gains that a data collection system could provide. How this is done, of course, will depend on the type and capacity of the registry chosen, but it could include examples of practical outcomes of different research projects based on registry

data, consequences of knowing the prevalence of different diseases/treatments/procedures in companion animals, possibilities of surveillance of contagious diseases, and so on.

Also important in the motivation of vets to report to a national disease registry is a feeling of trust that the information provided to the system will not be misused and that such participation will not generate mistrust among clients. Moreover, the governance of data in the disease registry has to be covered by an institution with no commercial interest in the information stored in the registry.

In the UK Dan O'Neill went to several institutions and stakeholders (academic, welfare, regulatory) to tell them about the VetCompass-project and ask them to support, agree or endorse the project. The existence of many such endorsements is bound to have a positive effect on the vets' willingness to participate. Generally, there seems to be very low levels of decision to opt-out from practice-based research, both among participating vets and among their clients (Jones-Diette, 2014, pp.95-96). This suggests that stressing the research purposes of a national disease registry could be effective in facilitating participation.

5. How should a national disease registry be managed and financed?

If the disease registry is to become a reality, questions about ownership, administration and financing have to be answered. In relation to ownership, two questions arise: Who owns the diagnostic code used to register data? Who owns the data registered?

In the Swedish/Norwegian Pyramidion, the diagnostic code is jointly owned by Djursjukvård and Dyreidentitet. Ownership of data based on this code is differently handled in Sweden and Norway. As already mentioned, there is no national disease registry in Sweden, and data on the diagnostic codes used are stored at the individual veterinary clinics and in insurance companies. In Norway, by contrast, diagnostic codes reported in the veterinary clinics are exported to a national registry that is coupled with the registry for dog and cat ID numbers. These databases are owned by Dyreidentitet and the Norwegian Veterinary Association. In the UK, the VeNom code is owned and managed by the VeNom Coding Group and data from individual veterinary clinics are reported to a national disease registry, VetCompass, owned by the RVC.

In the survey undertaken by Hartig et al. (2013) on stakeholder attitudes to an equine health and disease database, the preferred location for ownership and management of such a database was either at the University of Copenhagen or at the Danish Agricultural Advisory Service (a limited partnership company that supplies professional knowledge to the agricultural sector). Vets preferred

the University. In an interview with representatives from the Danish Veterinary Association it was emphasized that it is important that a national disease registry is owned and managed by a public, impartial authority. The Danish Veterinary and Food Administration was suggested.

Another possibility, and one presented by some participants in the equine survey conducted by Hartig et al. (2013), is co-ownership of the database by several stakeholders. This is also a possibility for a companion animal disease registry. However, to ensure impartial ownership and the trustworthiness of the registry, it is suggested that the University or the Danish Veterinary and Food Administration should own the data, and that a board with members from different stakeholder groups could run and manage the disease registry.

Developing, implementing and running a national disease registry will involve expense. As diagnostic codes already exist, it would be beneficial to use some of these instead of developing a wholly new diagnostic code. Some of the existing codes are 'open access' and some will require a relatively small investment. The developers of the Swedish/Norwegian Pyramidion mentioned the possibility of the Danish Veterinary Association or some other Danish stakeholder buying into the ownership of their diagnostic code. This would come at a cost, of course, but at the same time it would enable Denmark to participate in the management and future development of the diagnostic code that results.

It is less clear at the moment who should cover expenses incurred in the running and management of a national disease registry (the data and the database). This will depend to a large extent on decisions about ownership and management of the registry. Applications for sponsorships/funding are a possibility. Another possibility is financing some of the expenses by charging fees to users of the data in the registry (e.g. researchers, companies, the medical industry, pet food/accessories).

In has been found, however, that some vets would be reluctant to report to a registry if they risk having to buy their own data back subsequently (Hartig et al. 2013). Allowing private companies to buy access to a disease registry could generate income, but it may also erode the trustworthiness of such a registry.

This opens up questions about who should be able to use the data in a national disease registry. From the information collected for this report there is no doubt that the main purposes of collecting data about companion animal health and disease in a national registry should be research on disease prevalence, and risk factors, surveillance and perhaps with time the development of improved

veterinary treatment. The description of the VetCompass system states that all use of VetCompass data has to have the primary purpose of improving animal welfare. This is to assure contributors to the system that their data will not be used for commercial purposes.

As already mentioned, the management of a national disease registry finally has to ensure that there is anonymity for contributors – for clients as well as vets. Therefore access to data in the registry must be managed and controlled by the management group overseeing the system.

Possible solutions

The information retrieved for this report points to several potential ways forward with the development and implementation of a national disease registry for companion animals in Denmark.

For a start, the purpose and ambition of a national disease registry must be decided upon. Here, at least two choices must be made: 1) Is the purpose of the registry to be able to dig out fine-grained information on specific diseases of interest to specialists in the field, or is it rather to enable us to draw a big picture of prevalence of disease and health status in Danish companion animals? 2) Should the focus be specifically on disease diagnoses, or should the registry rather allow us to monitor a broader range of information on companion animals the vet examines?

Depending on the answer to the first question, the focus should be either on a patchwork of specialized registries or on a generic registry; and depending on the answer to the second questions, more or less focus should be on including various forms of measurement (e.g. body composition score) and intervention (e.g. euthanasia and neutering) in the registry.

Regardless of the choices made here, the registry should keep ID information on participating clinics and individual animals. This ID information is essential to avoid double counting of animals, and it may make it possible to couple data in the disease registry with data in other registers, such as breeding program registries. However, anonymity to anyone contributing data to the registry should be assured – for example, via encryption codes. Strict measures should be in place to ensure that the registry complies with Danish data protection legislation.

Regardless of the type of registry settled upon, it is important to consider how many participating veterinary clinics are needed for the data body in the registry to be sufficiently large and valid. A

reasonable approach is to start out with a segment of the Danish veterinary clinics, and to then seek to expand participation over time. Specifically, an obvious possibility would be to start by engaging veterinary clinics that are already ISO-certified or working to achieve ISO certification.

Moreover, it would be beneficial to encourage vets to keep detailed, well-structured records of their patients and their treatments. Mandatory record keeping should be introduced, as has happened already in other countries, but just as important here is more education and information for vets about the many benefits of good record keeping.

As to the coding system for a national disease registry, there are (at least) five distinct possibilities:

1. Becoming part of the Nordic cooperation, the Pyramidion
2. Basing a system on VeNom coding, with the possibility of collaboration with VetCompass
3. Basing a system on the SNOMED (veterinary) system
4. Developing a system that utilizes information in the free text of veterinary records
5. Developing independent registries for certain purposes, that are linked with the existing management software systems

The first three options are differentiated mainly by their choice of diagnostic code to be used in the system, and the possibilities of cooperation with organizations in other countries.

The choice of a coding system does not in itself create a disease registry. Clearly, however, this choice must be made with the envisaged purpose of the registry very much in mind.

It is possible to become part of Pyramidion to differing degrees, either by buying access to the diagnostic code or by buying into ownership and management of the system. Whereas the first of these two options will be cheapest, the latter will make it possible for Denmark to influence future developments within Pyramidion. Sweden and Norway are already working on implementation of Pyramidion, so Denmark will be able to benefit from their experience with the technicalities of transferring data, educating users, and so forth. Another important benefit of becoming part of the Pyramidion operation is that this would offer further opportunities of cooperation between the Nordic/Scandinavian countries. With a common diagnostic code and access to data collected in Sweden and Norway, studies comparing health and disease status in the Nordic countries become feasible, just as disease surveillance across borders will be a possibility.

Basing a system on the VeNom coding system has the advantage that the VeNom code is available free of charge. Also the VeNom coding system is already up and running in the VetCompass system which today holds data from over 450 veterinary practices and more than 4 million animals in the UK, as well as data from Australian veterinary practices. In a collaboration with VetCompass, Denmark will surely also be able to benefit from the many experiences that people in the UK have had working with this system in relation to data transfer, the recruitment of vets, and other matters. Although Denmark would not be on the group managing the VeNom code, it is possible to suggest improvements and/or alterations to the code. One benefit of the VeNom code from a research point of view is that it encompasses codes for veterinary procedures as well as some diagnostic tests and presenting complaints in addition to diagnostic codes.

Basing a system on the veterinary subdivision of SNOMED could prove very useful with time, since the Danish human healthcare sector is converting to the SNOMED system. It is possible that more information and assistance could be obtained by contacting IHTSDO and AAHA, but we have not been in contact with any users of the AAHA coding system. The Danish PMS Novax provides PMS solutions for both human doctors and vets, and the president of the company, Ole Abildgaard, emphasizes the importance of standardizing human and veterinary systems in relation to the issue of One Health, i.e. to enable collaboration across veterinary and human medicine to achieve health benefits for humans and animals. For a companion animal disease registry to contribute to One Health initiatives, it will need to be accepted and used by most practising vets; it will also have to cover the relevant zoonotic and infectious diseases, providing important information also for human medicine.

A data extraction system which can utilize information in the free-text fields of veterinary records and report the disease data into a national database would help with the problem presented by the fact that many vets are not using diagnostic codes. It would also help with the variable validity of diagnostic codes. It seems, however, that systems of this sort are currently at a developmental stage. Therefore choosing to base a Danish disease registry for companion animals on a free-text-search system would probably involve a great deal more work in the development phase than systems based on diagnostic codes. The latter can more easily be implemented at this stage.

However data are coded and/or reported to a national disease registry, a decision has to made on who should own and manage the registry. Depending on the choice of diagnostic code system, the obvious candidates for ownership/co-ownership of the coding system are the Danish Veterinary

Association and the Danish Veterinary and Food Administration. However, the University of Copenhagen could also own or administer the diagnostic code. So far as ownership of the disease data/database is concerned, we believe the simplest solution is for the registry to be owned by, and located at, the University, managed by a board of members representing key stakeholders.

To move things on, resources are required. Developing and implementing a sustainable Danish disease registration system for companion animals therefore requires several stakeholders, including the Danish Veterinary and Food Administration, the Danish Veterinary Association, the University of Copenhagen, and various private and public funders of veterinary research, to collaborate on a funding model.

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