Do we need an equine biobank in the UK?

Online Survey Results

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Background

• The past decade has seen phenomenal progress being made in the field of genetics, including the mapping of genes, identification of gene variants and sequencing of DNA.

• The most significant development in horse genetics was the release of the draft genome sequence of the horse in 2007. This was followed by the creation of the Illumina Equine SNP50 BeadChip, a technology which allows us to characterise each horse’s genome in great detail.

• In order to exploit these new genotyping technologies and to help us understand complex traits and diseases, large collections of DNA samples from well-characterised animals are needed.

• One of the principal limitations to progress at this time is a lack of samples and associated animal data. In response to this challenge, the medical genetics community has begun establishing national and international biobanks (e.g. UK Biobank, Generation Scotland) which are organised collections of biological samples and associated data.

• Through an extensive literature review, interviews with representatives from the equine industry and an online survey aimed at the general horse owning public, we aim to find out whether an equine biobank could be a useful resource for the UK equine industry.

• This report summarises the results of the online survey part of the project which ran from 26th January – 4th May 2012.
Data Collection

• Participants
  – There were no restrictions on who could complete the questionnaire
  – Responses were anonymous and no personal data was collected
  – The survey was advertised through:
    • The distribution of a small number of flyers and posters
    • Emails sent to breed societies listed as data providers on the National Equine Database website and with contact email addresses or websites
    • An article in Horse and Hound magazine
    • Various online news articles, e.g. BBSRC, The Roslin Institute, Biosciences KTN

• The questionnaire
  – The questionnaire comprised of a total of 20 questions
  – Questions were in three sections with different themes
    • Section 1: Demographic data
    • Section 2: Prior knowledge of biobanks
    • Section 3: Creation of a UK equine biobank
There were a total of 128 participants, 108 of which completed the questionnaire (only complete responses were analysed).

Over half participants classed themselves as hobby or amateur riders.

8% of participants classed themselves as breeders.
Results: Demographic data

Involvement in competition

- 16% of participants said they do not compete
- Over half participants competed in dressage, showjumping or eventing
- Other disciplines represented in much smaller numbers included: driving, racing, para-dressage, reining and polo
Results: Demographic data

Membership of organisations

- The organisation with the most members was the British Horse Society
- 20% of participants were not a member of any equine organisation
- Other organisations represented were: breed societies, BEVA, BETA and riding clubs
Results: Demographic data

Horse ownership

- 61% of participants owned at least one horse
- Of those with horses, 65% were single-horse owners and 21% had more than 5 horses
- Over a quarter of horse owners had their horse registered with a native horse and/or pony breed society, e.g. Highland Pony Society, Clydesdale Horse Society
- 16% of horses were registered with an overseas studbook, e.g. KWPN
- Other societies represented included: Coloured Horse and Pony Society, Arab Horse Society
Results: Prior knowledge of biobanks

Participants read the following:

“Biobanks have traditionally been associated with biomedical research. They are collections of biological materials (such as blood and/or tissues) and personal data (medical records, lifestyle data) from large numbers of people. Using such biobanks, researchers can identify the genetic and environmental factors associated with the risk of certain diseases. This information can help to improve prevention, diagnosis and treatment. Critics, however, raise questions about the privacy and confidentiality of biobanks and have concerns over commercial interests and regulation. As scientists unravel the genetic code of many animals, including the horse, veterinary researchers are creating collections of animal biological samples with associated data for use in similar genetic studies. Data in this setting may include diagnostic test results, treatment received, etc.”

➢ When then asked what they would like to know more about before deciding whether or not to vote in favour of a biobank, people were most interested in finding out about the potential benefits of the biobank and least interested in who would pay for the biobank

➢ Exactly half the participants had heard about biobanks prior to taking part in the survey and of these:
  – 50% had actively engaged with the topic of biobanking (i.e. talked about or searched for information about biobanks occasionally or frequently)
  – Most (61%) had never talked about or searched for information about equine biobanks
  – More people had talked about biobanks than searched for information about them
Results: Creation of a UK equine biobank

Potential utility of the biobank

- When asked how important some suggested uses of the biobank were, participants ranked them as follows (1=most important; 5=least important):
  1. Genetic research of disease
  2. Breeding - to reduce disease by marker assisted selection
  3. Conservation
  4. Genetic research of performance traits
  5. Breeding – to improve performance by marker assisted selection
- Below are a number of quotes from survey participants relating to potential uses of a biobank:

  “Could be very useful to the veterinary profession under the right management”

  “I would be interested to know if this could detect the ancestry of my horse and any potential health problems before they manifest themselves”

  “….identifying stolen and lost horses as it can't be disguised or removed”

  “A biobank would be a useful tool in breeding”

  “….beneficial for proving parentage”
Results: Creation of a UK equine biobank

Sample and data collection methods

- When asked about the collection of data and biological samples for a biobank:
  - Less than 15% of participants were concerned about the collection of: blood samples (left over from veterinary procedures), hair (with roots attached), buccal (cheek) swabs, nasal swabs, performance records, lifestyle information, pedigree
  - Roughly a quarter of participants were slightly concerned about the collection of: blood samples (taken solely for the purpose of the biobank) & veterinary records

- When asked about how biological samples should be collected, the preferred options were:
  1. Collection by the vet during a routine visit
  2. Collection by the vet following the admission of a horse for treatment
  3. Collection by the participant (only applies to hair, buccal swabs and nasal swabs)

- More than 80% of participants would be willing to provide updates to an online profile for their horse regularly (81%) or on request (89%)
- More than 80% of participants would be happy for researchers to access their horse’s performance records (81%) and veterinary records (88%), provided their permission was sought first
- Less than 1/3 of participants would be happy for researchers to access their horse’s veterinary records without their permission
- 14% of participants would prefer for their horse’s sample and associated data to remain anonymous
Results: Creation of a UK equine biobank

Funding for the biobank

- When asked who should pay for the biobank, the options most participants agreed with were:
  1. People who use the samples and information should pay for the biobank
  2. Participants would be happy to pay a small fee but would expect something in return
  3. Equine organisations should pay for the biobank
- 29% of people agreed that they did not know who should pay for the biobank

Concerns about a biobank

- When asked about their concerns surrounding the biobank, participants were most worried about:
  1. Potential effects of genetic test results on insurance premiums
  2. Confidentiality of data
  3. Potential effects of genetic test results on sale values

“I would not pay”

“Cost would put me off”

“I would be concerned of the effect on my insurance premiums”

“My concern would be who would have access to my data”
Results: Creation of a UK equine biobank

- **91% of participants** were supportive of the UK having an equine biobank
- **93% of participants** were willing to provide samples from and information about their horse(s)

When asked why they might not provide samples, participants said:

- “I would be concerned of the effect on my insurance premiums and coverage if my horses were found to be genetically predisposed to certain conditions”
- “I am not convinced welfare is the top priority and do not want to contribute to perverse use in relation to breeding for performance”
- “Cost involved and lack of security of records and biological samples”
- “I would be unwilling to release information about my horses to researchers without prior permission as I would have no idea of their interest and qualifications and I would like to know the nature of the research the data would be used for before my horse’s information is accessed”
- “I would want assurance that my horse would not have to have anything invasive or unpleasant done”
- “I would be willing to provide samples if I was satisfied the scheme was properly regulated and confidential, and there was no cost to myself in terms of time and cost”
- “I would be concerned about potential purchasers or competition authorities having access to horses’ records”
- “I would be concerned about the use of tissues being used for cloning and being used for living animal experiments”
Conclusions

• In general, the idea of having an equine biobank in the UK was positively received.
• Results from a corresponding survey on the Horse and Hound website showed that 85% of people would contribute their horse’s DNA to a biobank. This suggests a slight positive bias in our study in which 93% of participants agreed they would contribute material.
• People were most interested in the use of a biobank to reduce disease, rather than to improve performance. This may be partly due to the background of participants, as there were few breeders and no professional riders in the sample.
• There was some concern regarding the impact of research outcomes on insurance premiums and sales values. Little concern was shown for a similar impact on breeding values, even by the 8% of participants who classed themselves as breeders.
• Participation in any future biobank is likely to depend on a number of factors including:
  – The cost of participation, both in terms of time and money
  – Whether horse owners agree with the way in the samples and data will be used
  – Whether horse owners trust the people in charge of the biobank to look after their (and their horse’s) best interests
• The results from this survey will be combined with additional information from an extensive literature review and interviews with representatives from the equine industry to form the basis of a feasibility study to determine whether a UK equine biobank would enable the horse industry to better exploit new genomic technologies.

“If I thought it was managed well and for the benefit of the industry I would definitely contribute.”
And finally..........

A big thank you to everybody who took part!

For more information about this project and about biobanks, go to: www.roslin.ed.ac.uk/john-woolliams/equine-biobank-project/