

# Uniform Donor History Questionnaire Task Force: Focus Groups

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# Background

- Methodology published in Nov 2000 Transfusion
  - 7 questions in this publication (Jan – Mar, 1999)
- UK travel and bovine insulin questions (Sept 1999)
- 13 additional questions for UDHQ Task Force (Feb – Apr, 2001)

# 1999 Focus groups: comments

- Demographics are in the publication (pg 1409).
- Compound questions are too long. Particularly if oral, they are long to remember. Recommended splitting up all compound questions targeted.
- A history of hepatitis before the age of 11 is too hard to remember.
- Use of the terms “liver disease” or “yellow jaundice” are vague and unnecessary.

## continued

- Cancer should be separate from other non-malignant diseases (lung and heart disease).
- If a diagnosis of CJD is associated with dementia, then asking a donor if they have CJD doesn't appear to make sense; they would be too sick to donate.
- A participant who was diabetic stated that they would not remember using bovine insulin if more than a few months prior to donation.

# 2001 Participant Demographics

	Group 1: business	Group 2: general	Group 3: general	Group 4: HS
Age	21-50	18-50	18-60	< 18
Gender	4 M	2M, 5F	1M, 5F	2M, 3F
Edu	12 <sup>th</sup> no diploma- some coll	Some coll – BA	HS - AS	HS no diploma
Race/Eth	All non- HW	2 non-HW, 5B	4 non- HW, 2B	5 non-HW
Donors	1	1	6	0

# 2001 Focus group: comments

- If questions are oral only, some are too long. If read by the donor, none of the questions are too long.
- Regardless of length, compound questions can be made more clear by splitting up.
- Removal of one or two unnecessary or redundant words will simplify the questions (i.e. “ever, even once”; omit “even once”).
- Cancer should be separate from other non-malignant diseases (lung and heart disease).

## continued

- The word “disorder” has a negative connotation. Change to “condition” which is used in other questions.
- Separate “transplant” from “graft” and include “bone marrow” in transplant.
- For IDU, if needle use is the issue, specifying only “drugs or steroids” misses other injections (i.e. vitamins, supplements).
- Regarding travel to Africa, “other medical treatment with a product made from blood” is not clear.

## continued

- Regarding jail or prison, also include juvenile hall and lock-up.
- Use of “prostitute” with “payment for sex” is unnecessarily redundant.
- Criteria for “lived in Africa” should be specified. Participants also wondered if extended travel to Africa was a risk.

# Participant Demographics

	Group 1: business	Group 2: minority	Group 3: HS
Age	Same	21 - 30	Same
Gender	Same	1M, 4F	Same
Edu	Same	Some coll-BA	Same
Race/Eth	Same	5B	Same
Donors	Same	1	Same

# Xenotransplantation

- Brief description of xenotransplantation and the rationale for questions was given.
- General comments:
  - It seems impractical to ask questions of all donors in order to detect such a small number of individuals at theoretical risk.
  - The two questions were too long and too complicated.

## continued

- Clarification needs
  - What is repeatedly?
  - Body fluids; what about urine, feces or vomit
  - What is deep kissing?
  - What if your exposure is to a partner who is not a family member, nor someone you are having sex with?
  - Toothbrushes, razors, etc; if you are exposed to body fluids, what difference does it make what the method was, and do the methods listed cover everything?