

17/49/42 supp material 6: Example site-specific report on results from notes review (WP1S1)

EDiPPPP Notes Review Feedback [EXAMPLE]

This report summarises notes review outcomes for [EXAMPLE SITE] - Full results for this site are provided in the accompanying file – [INSERT FILENAME].

Reviewers (i.e., principal investigators and other colleagues at partner sites) were asked to assess each case against ‘referral’ criteria provided by NHSBT.

Specialist colleagues at NHSBT acted as **evaluators** for assessments submitted by reviewers and provided feedback on whether they agreed with the reviewer assessment (given the information provided).

- *Note 1:* all references to ‘accept/decline/uncertain’ relate to whether or not a threshold of evidence has been met for **referral to NHSBT** (i.e., it does **not** mean that a threshold for *retrieval* of eye tissue has been determined).
- *Note 2:* tables contain all free-text comments on assessment outcome from the reviewer (black) and/or evaluator (red). In cases where no comment appears, this is because no comment was provided in that case (as this was an optional field for the reviewer/evaluator to use as needed).
- *Agreement rate between reviewer and evaluator (i.e., any outcome) – 79% (n=158 cases)*
- *Acceptance rate for referral as agreed by reviewer/evaluator against assessment criteria – 23% (n=45 cases)*

Other outcomes of assessment (reviewer and evaluator, n=42)

Reviewer decisions regarding acceptance for referral

- There were **no cases** where the evaluator **disagreed** with the reviewer assessment that the patient was **acceptable** for referral to NHSBT.

Reviewer decisions regarding decline for referral.

- In 28 cases, where the reviewer had indicated that the patient was a **decline** for referral to NHSBT, the evaluator indicated **acceptance** (Table A).
- Twenty-seven of these cases involved the reviewer **declining** referral due to the patient reaching the age cut-off (<85 years). In these cases, the evaluator had indicated that ‘age’ would not be a reason for exclusion in the absence of any history of ocular disease.
- One further case of reviewer assessment of **decline** where the evaluator indicated **acceptance** related to the recent onset of confusion.
- There were four further cases in which the reviewer had indicated **decline**, while the evaluator was **uncertain** and indicated that more information was needed (Table B).

Reviewer uncertainty regarding referral

- In eight cases, the reviewer indicated that they were **uncertain** regarding eligibility for referral. In these cases, the evaluator indicated **acceptance** (Table B below).
- In two cases where the reviewer has indicated **uncertainty**, the evaluator indicated a **decline** (Table D below).

Key messages:

- There was a high degree of agreement (any outcome) between the reviewer and evaluator (79%)
- The 27 cases in which the reviewer had declined referral based on age cut-off (and the evaluator had indicated inclusion) involved a correct application of the age-cut off as understood at the time by the reviewer. The reason for disagreement was an increase in age cut-off at NHSBT after the review had begun (which was not communicated to the clinicians or the research team).
- The majority of disagreements at this site involved the reviewer correctly applying an age cut-off criterion that was understood to be in place at the time. However, evaluator response indicates that age range for eye donation is not a fixed criterion for NHSBT and may be influenced by the need for eyes on that day/week.

Table A – Reviewer Decline with Evaluator Accept

EDiPPPP Case ID	Comments (reviewer = black ; evaluator = red)
P05102	Above age cut off: No Ocular history so patient eligible to donate at this age, no other contra-indications noted
P05802	Above age cut off. No upper age limit and no Hx of ocular surgery
P06002	Above age cut off. No Upper age limit, no ocular surgery
P06102	Above age cut off. No upper age limit, no Ocular surgery
P07302	Above age cut off: No upper age limit as no ocular history. I would accept
P08502	Above age cut off: No Hx Ocular Disease or Sx, I would accept
P08602	Above age cut off: No Hx Ocular Disease or Sx, I would accept
P08802	Above age cut off: No Hx of ocular disease or Sx, I would accept
P08902	Above age cut off: No Hx of ocular disease or Sx, I would accept
P09502	Above age cut off. No Hx ocular disease or Sx, I would accept
P10202	Above age cut off; confusion. No Hx of ocular disease or Sx. I would accept. Confusion secondary to CVA
P11302	Above age cut off. No Hx of ocular disease or Sx: Accept
P11702	Above age cut off: No Hx of ocular disease or Sx: Accept
P11902	Above age cut off. No Hx of ocular disease or Sx: Accept
P12202	Above age cut off, mild confusion. No Hx Ocular disease or Sx, mention of confusion in Hx likely related to terminal phase of pneumonia: accept
P12402	I think the history of possible recent confusion would have been a contraindication: Recent onset of confusion likely to be related to terminal phase of pneumonia. Accept
P12502	Above age cut off. No Hx of ocular disease or Sx: Accept
P13302	Above age cut off. No Hx of ocular disease or Sx: Accept
P13602	Above age cut off. No Hx of ocular disease or surgery: Accept
P14202	Above age cut off; No Hx of ocular disease or Sx: Accept
P14302	Above age cut off - just: No Hx of ocular diese or Sx: Accept
P16802	Above age cut off. No Ocular Hx or Sx Accept
P16902	Above age cut off. No Ocular Hx or Sx. Accept
P17702	Above age cut off. No Ocular Hx or Sx Accept
P18102	Above age cut off. No Ocular Hx or Sx Accept

P18302	I feel that given that he was so near the age cut off, had multiple eye conditions and had no family to ask permission from, he was not a suitable eye donor. Meets criteria for donation. I would accept
P19202	Above age cut off. No Hx Ocular disease or Sx. I would accept
P19602	Above age cut off No Hx Ocular disease or Sx. I would accept

Table B - Reviewer Decline and Evaluator Uncertain

EDiPPPP Case ID	Comments (reviewer = black ; evaluator = red)
P06802	Above age cut off, and referral to coroner would also have likely precluded eye donation. Unable to assess due to no COD but TES would discuss with the coroner to seek a lack of objection (usually given for palliative care cases), not over age for eye donation as no Hx of ocular surgery
P08702	Above age cut off, and I think haematological condition would also have been a contraindication: Would need IgG below 15g/l and a normal free light chain ratio in order to accept
P13702	Above age cut off: No Hx of ocular disease or surgery: Accept. Would need cause of death as referred to Coroner
P15402	Above age cut off, plus confusion. Confusion and hallucinations sound like delirium and not dementia. No Hx of ocular disease or Sx . More information as to the presentation of confusion: was it at EOL or medication related? ?

Table C – Reviewer Uncertain and Evaluator Accept

EDiPPPP Case ID	Comments (reviewer = black ; evaluator = red)
P05502	Unsure whether delirium without a concrete cause would be a contraindication. Delirium not a reason to defer
P08402	I think likely was potential donor but given trans-gender it is possible that the life-style risk screening done with family by NRC would have turned up a contra-indication Assessment of the donor should be undertaken according to the gender assigned, which would negate most lifestyle contraindications. I would refer to NRC pending full family interview
P09402	With so many eye conditions, I am not certain he would have been accepted as a donor, given that he was also relatively elderly. Age and history do not contraindicate this donor, accept.
P10402	I think she probably was a potential donor and would have been certain enough to offer donation discussion. No reason to be unsure, no contraindications: Accept
P10802	I do not think they would have accepted for donation given multiple eye conditions and so near the age cut off: No reason to decline by age or Hx. Accept
P13102	Hypersensitivity pneumonitis due to many years exposure to a cockatiel, raised avian precipitins: Acceptable
P15002	Raynaud's is a form of vasculitis, but its effects are limited to the blood supply to the hands, and I do not know if it would be a C.I for eye donation. It can be seen in other conditions which also affect the eyes (such as systemic sclerosis) so I would guess it probably is a C.I. Raynauds is acceptable and there is no suspicion of systemic sclerosis, etc: Accept
P18502	I think probably was eligible, but I am not absolutely certain about the rheumatoid arthritis. I would accept with Hx Rheumatoid Arthritis

17/49/42 supp material 5: Demographic characteristics of patient cases by site type (n.b. greater intensity of blue shading in % column indicates closer proximity to 100%)

		HC (n=600)		HPC (n=600)		All Sites (n=1200)	
		n	%	n	%	n	%
Age Group	21-30	2	0.3%	3	0.5%	5	0.4%
	31-40	16	2.7%	7	1.2%	23	1.9%
	41-50	29	4.8%	18	3.0%	47	3.9%
	51-60	90	15.0%	40	6.7%	130	10.8%
	61-70	163	27.2%	80	13.3%	243	20.3%
	71-80	192	32.0%	140	23.3%	332	27.7%
	81-90	92	15.3%	217	36.2%	309	25.8%
	>90	16	2.7%	95	15.8%	111	9.3%
Gender	Female	285	47.5%	289	48.2%	574	47.8%
	Male	315	52.5%	311	51.8%	626	52.2%
Ethnicity	White British	449	74.8%	530	88.3%	979	81.6%
	Other Mixed	57	9.5%	8	1.3%	65	5.4%
	Not recorded	39	6.5%	16	2.7%	55	4.6%
	Other White	19	3.2%	20	3.3%	39	3.3%
	Indian	14	2.3%	6	1.0%	20	1.7%
	Pakistani	9	1.5%	4	0.7%	13	1.1%
	Black Caribbean	3	0.5%	1	0.2%	4	0.3%
	White and Black Caribbean	3	0.5%	3	0.5%	6	0.5%
	White and Asian	3	0.5%	0	0.0%	3	0.3%
	Other Asian	1	0.2%	2	0.3%	3	0.3%
	Chinese	1	0.2%	0	0.0%	1	0.1%
	Any other ethnic group	1	0.2%	1	0.2%	2	0.2%
	White and Black African	1	0.2%	3	0.5%	4	0.3%
	Bangladeshi	0	0.0%	2	0.3%	2	0.2%
	Black African	0	0.0%	1	0.2%	1	0.1%
	Other Black	0	0.0%	1	0.2%	1	0.1%
White Irish	0	0.0%	2	0.3%	2	0.2%	

Table D - Reviewer Uncertain and Evaluator Decline

EDiPPPP Case ID	Comments (peer reviewer = black ; peer evaluator = red)
P09002	I am pretty sure, but not certain, that amyloid is a contraindication to donation. Amyloid deposits not a contraindication but amyloidosis is a decline. Decline donor
P17202	I feel so many eye conditions in a lady so close to the age cut off would not have been accepted by NRC. Nil in ocular Hx to decline for eye donation.