

**Assessing Patient Preferences in Rare Diseases: Direct Preference Elicitation in the
Rare Chronic Kidney Disease, Immunoglobulin A Nephropathy**

**Assessing Patient Preferences in Rare Diseases: Direct Preference Elicitation in
Immunoglobulin A Nephropathy**

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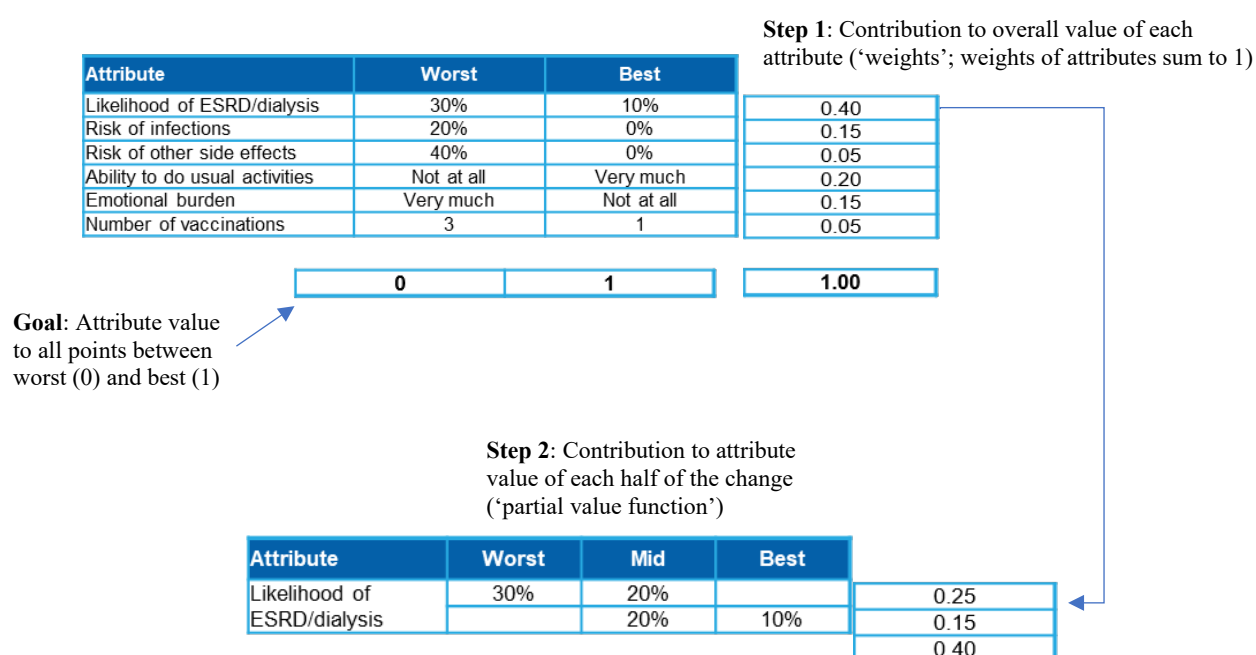
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SUPPLEMENTARY MATERIAL – PREFERENCE ELICITATION AND BENEFIT RISK ASSESSMENT

Preference elicitation

The preference elicitation involved two steps. Step 1 estimated the weight that each participant placed on the ‘swings’ in attributes, which are then normalized to sum to 1. Step 2 estimated the partial value function that described the relative value of changes withing each attribute.



Step 1: Swing weighting

In the first part of the exercise, participants ranked the improvements shown for each attribute (‘swing’) in the order of importance. Then 100 points was allocated to the first ranked attribute and participants were asked to rate the relative importance of the improvement in other attributes on a scale of 0-100 over a series of pair-wise tasks.

Step 1a: Rank ‘swings’ in order of importance

Step 1b: Pairwise comparison in order of ranks

Step 1c: Discuss / validate trade-offs

Step 1d: Normalise ‘weights’ to sum to 1

Attribute	Worst	Best	Weight
Likelihood of ESRD/dialysis	30%	10%	100
Risk of infections	20%	0%	37.5

Pairwise comparisons were undertaken between attributes ranked first and second, second and third, third and fourth, etc. In order to validate participants' responses, an additional rating task was included where participants were asked to compare between the first and third-ranked attribute as part of a consistency check.

Pairs of attribute comparisons

<u>Top row</u>	<u>Bottom row</u>
First ranked attribute	Second ranked attribute
Second ranked attribute	Third ranked attribute
Third ranked attribute	Fourth ranked attribute
Fourth ranked attribute	Fifth ranked attribute
Fifth ranked attribute	Sixth ranked attribute
First ranked attribute	Third ranked attribute

Consistency test

Step 2: Partial value function elicitation

Participants were asked to value improvements within each attribute. Participants were told that levels 1 and 2 on the attribute had a score of 0 and 1 respectively and were asked to score level 3 on a scale of 0–10.

Step 2a: Score levels of each attribute

Attribute	Level	Score
Likelihood of ESRD/dialysis	30%	0
	20%	1
	10%	3

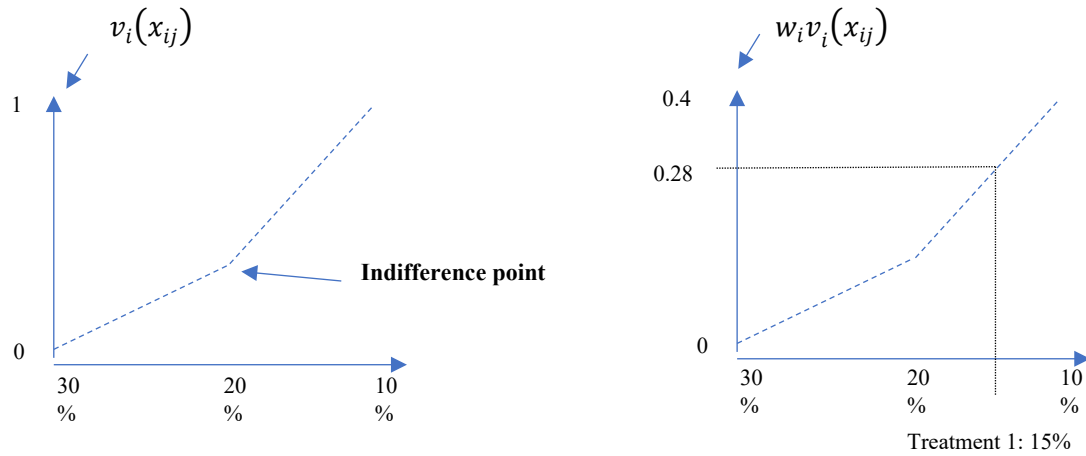
Step 2b: Discuss / validate trade-offs (qualitative insights)

Step 2c: Normalise scores to sum to 1

Treatment evaluation

Step 1: Estimate the value of each treatment

The value of a treatment on each attribute was estimated for each respondent, as illustrated for ESRD risk in the figure below.



The overall value of the treatment across all attributes was then estimated for each respondent as:

$$U_j = \sum_{i=1}^n w_i v_i(x_{ij})$$

Where

U_j is the overall value generated by treatment j

w_i is the weight associated with attribute i ,

v_i is the partial value function for attribute i

x_{ij} is the performance of treatment j on attribute i

Step 2: Compare the value of treatment

Each respondent's valuation of each treatment was compared to generate a respondent-specific treatment ranking. The frequency of ranking for each treatment was then estimated across respondents.

Resp.	Total value			Rank treatment		
	T1	T2	T3	T1	T2	T3
1						
2						
3						
4						
5						
.....					

Maximum acceptable risk infection, T3 vs	
T1	T2
.....	

Step 2b: Estimate the maximum level of e.g. risk of infection that will result in T3 having the same total value as T1 or T2



Rank 1	%	%	%
Rank 2	%	%	%
Rank 3	%	%	%

Step 2a: Rank total value of treatment for each respondent and the rank probability