Valuing health at the end of life
DSU preference study

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NICE end of life criteria

- Criteria that need to be satisfied for NICE's supplementary end of life policy to apply are currently as follows:

C1	The treatment is indicated for patients with a short life expectancy, normally less than 24 months
C2	There is sufficient evidence to indicate that the treatment offers an extension to life, normally of at least an additional three months, compared to current NHS treatment
C3	The treatment is licensed or otherwise indicated, for small patient populations

NICE end of life criteria

- Placing additional weight on survival benefits in patients with short remaining life expectancy could be considered a valid representation of society's preferences
- But the NICE consultation revealed concerns that there is little scientific evidence to support this premise

NICE end of life criteria

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DSU project

Preference study

- Aim: to validate that giving higher priority to EoL treatments is consistent with public preferences
- Small scale (n=50)
- Simple choice study administered using face-to-face interviews
- Preceded by a pilot / exploratory study using a convenience sample (n=20)
- Findings will inform the design of the weighting study

Discrete choice study

- Aim: to determine a set of cut-offs / weightings that is commensurate with public preferences
- Large scale (n=4,000)
- Discrete choice experiment administered using web-based survey

Summary of findings from pilot

- Most respondents preferred to treat the end of life patient
  - Driven by a concern for how much time one has to 'prepare for death'
- Very few respondents expressed 'no preference'
- Quality of life improvement may be more important than life extension in the end of life scenario
- Probing questions revealed some rationales that we had not anticipated
- Some aspects of the design found to be problematic, but on the whole the study was completed successfully and the design was found to be feasible

Study hypotheses

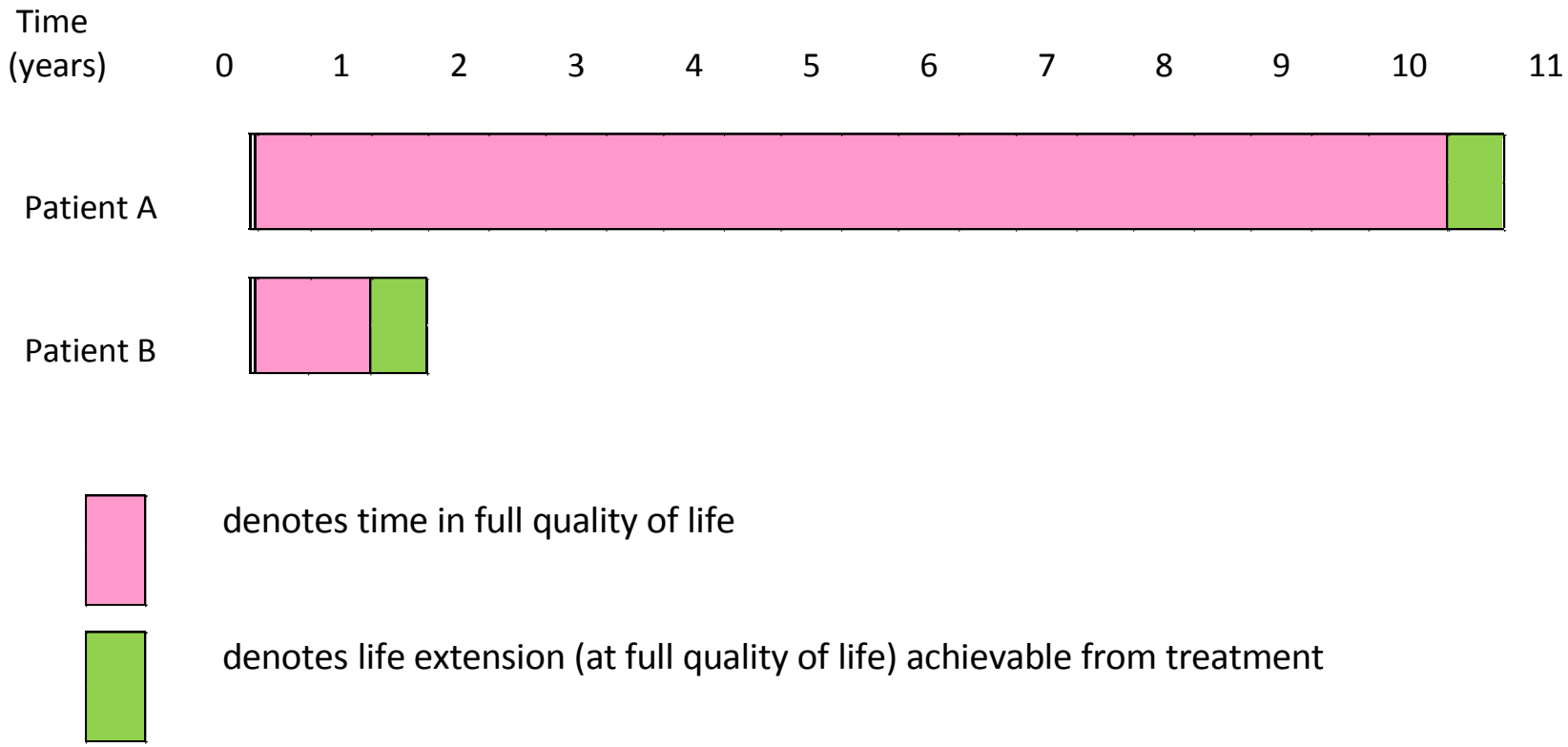
1. The majority of people wish to give **higher priority to the treatment of end of life patients** than to non-end of life patients.
2. Concern about **age is not a motivating factor** for any observed preference for giving higher priority to the treatment of end of life patients.
3. **Time preference is not a motivating factor** for any observed preference for giving higher priority to the treatment of end of life patients.
4. The majority of people wish to give **equal priority to life-extending and quality of life-improving treatments** for end of life patients.
5. Concern about **age is not a motivating factor** for any observed preference for giving higher priority to either life-extending or quality of life-improving treatments for end of life patients.
6. Any preference for giving **higher priority to life-extending end of life treatments** is **outweighed by the preference for giving greater priority to quality of life-improving treatments** for non-end of life patients.

Design

- Face-to-face interviews
- Six simple choice exercises ('scenarios')
  - preceded by a warm-up exercise
- Respondents asked to choose which of two hypothetical patients they would prefer the health service to treat, or whether they had no preference between the two
- Respondents then asked to indicate (using tick-box questionnaire) the reasons for their choice
- Scenario description read aloud to respondent by trained interviewer; supplemented with paper-based diagrammatic illustration and tabular summary of key information

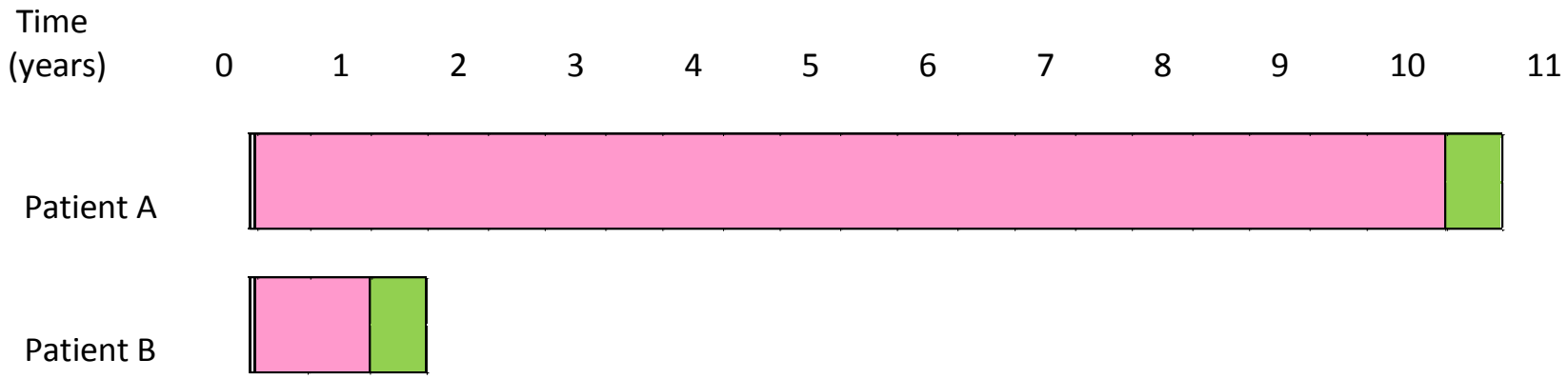
Scenario S1

- Both patients are same age today (Time=0)



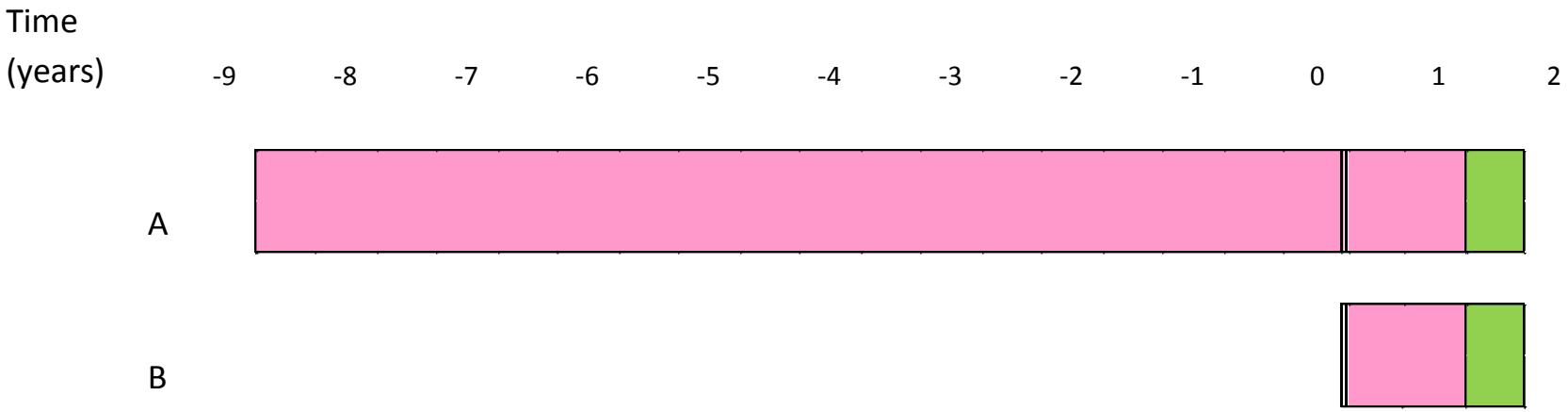
Scenario S2

- Patient B is 9 years older than patient A today



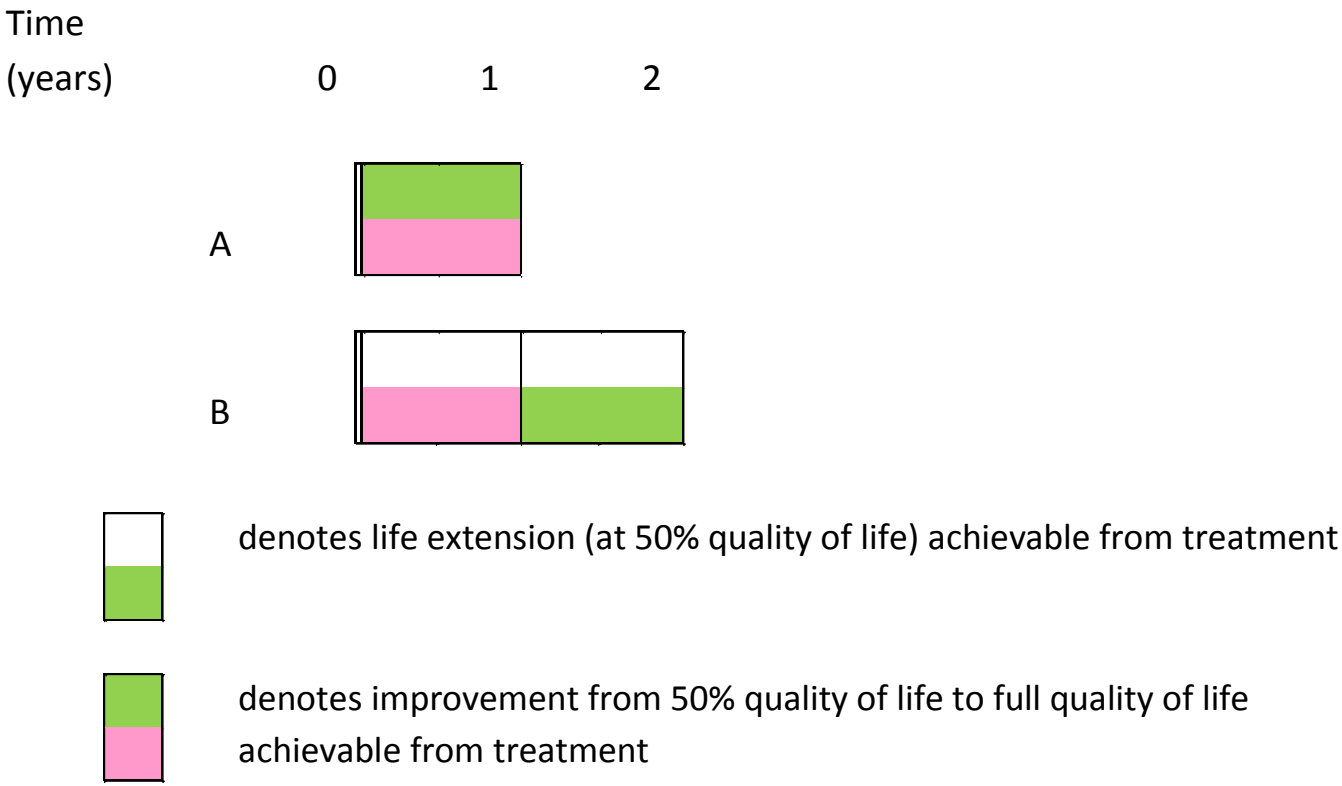
Scenario S3

- Both patients are same age today



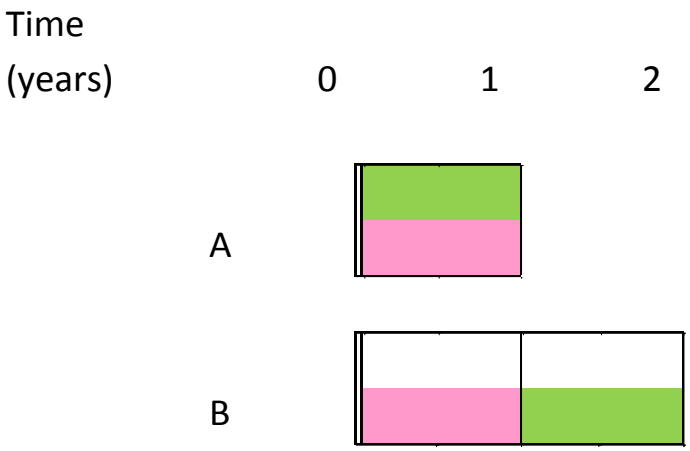
Scenario S4

- Both patients are same age today (30 years old)



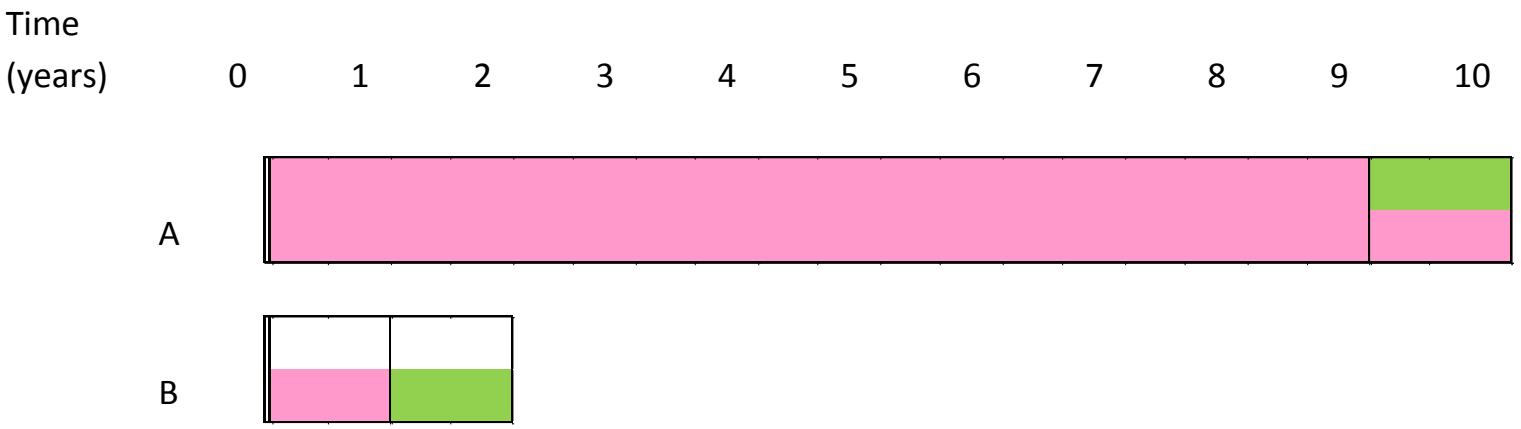
Scenario S5

- Both patients are same age today (70 years old)



Scenario S6

- Patient B is 9 years older than patient A today



Tick-box questionnaire

- ❑ delivers the largest benefit
- ❑ most fair
- ❑ delivers the benefit today
- ❑ benefits the patient who is closest to death
- ❑ benefits the patient who has longer left to live
- ❑ benefits the patient with less time to prepare for death
- ❑ benefits the patient who can make the most out of their remaining time
- ❑ benefits the patient who is worse off
- ❑ benefits the patient who is younger today
- ❑ benefits the patient who is older today
- ❑ benefits the patient who will die at a younger age
- ❑ benefits the patient who will die at an older age
- ❑ better to improve health than to extend life in this situation
- ❑ better to extend life than to improve health in this situation
- ❑ both patients are equally deserving of treatment
- ❑ unfair to choose between the patients
- ❑ unwilling to choose between the patients
- ❑ none of the above

Tick-box questionnaire

- ❑ delivers the largest benefit
- ❑ **most fair**
- ❑ delivers the benefit today
- ❑ **benefits the patient who is closest to death**
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- ❑ **benefits the patient with less time to prepare for death**
- ❑ benefits the patient who can make the most out of their remaining time
- ❑ **benefits the patient who is worse off**
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- ❑ benefits the patient who will die at a younger age
- ❑ benefits the patient who will die at an older age
- ❑ better to improve health than to extend life in this situation
- ❑ **better to extend life than to improve health in this situation**
- ❑ both patients are equally deserving of treatment
- ❑ unfair to choose between the patients
- ❑ unwilling to choose between the patients
- ❑ none of the above

Sample

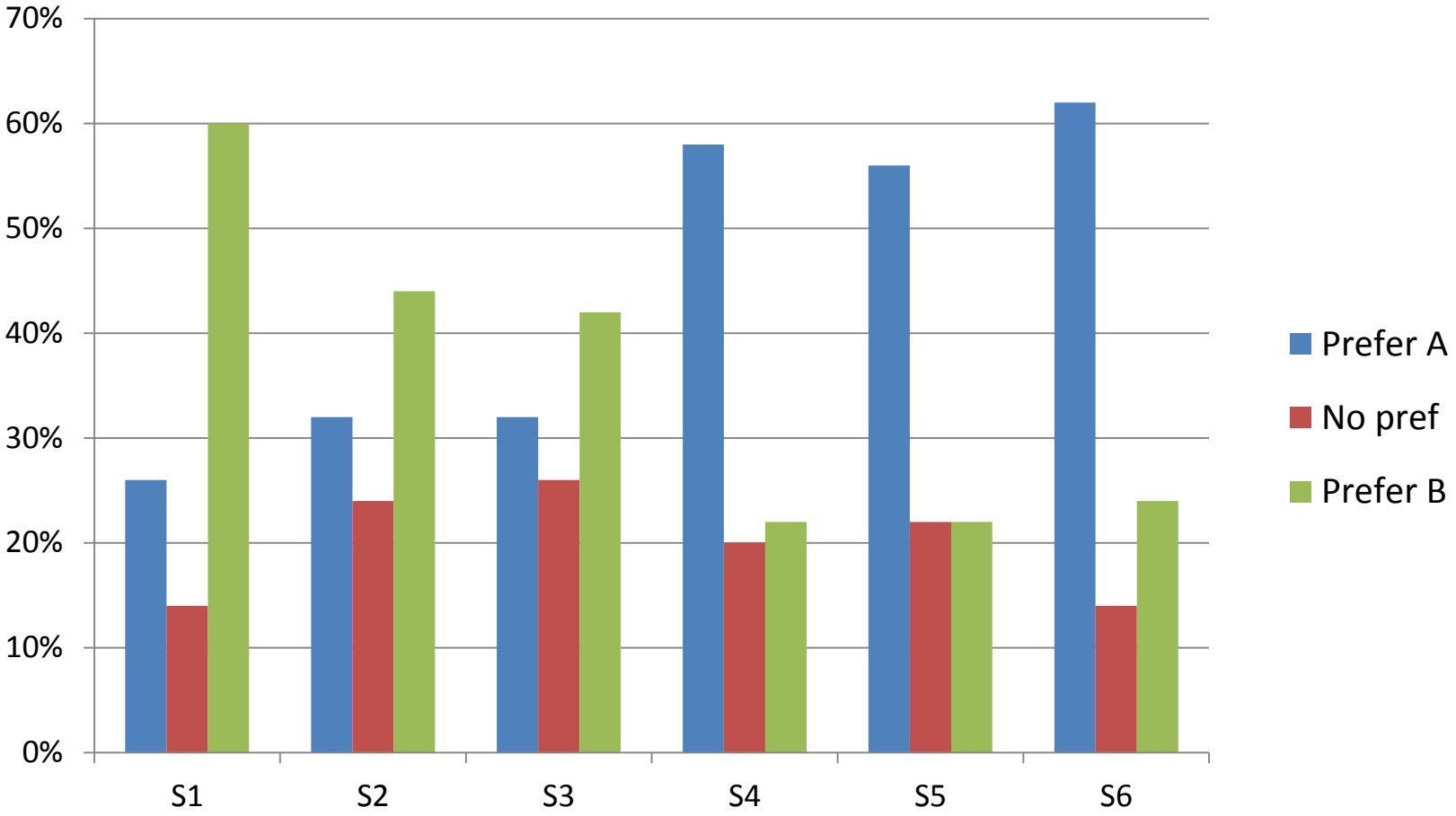
- 50 respondents
- Members of the general public living in London and Kent
- Broadly representative of the general population in terms of age, gender and social grade
- Sample recruitment and interviews undertaken by a market research agency with considerable experience in preference elicitation studies
- Respondents given a small cash incentive to participate

Results

- Aggregate response data for all scenarios

	S1	S2	S3	S4	S5	S6
Prefer to treat patent A	13 (26%)	16 (32%)	16 (32%)	29 (58%)	28 (56%)	31 (62%)
No preference	7 (14%)	12 (24%)	13 (26%)	10 (20%)	11 (22%)	7 (14%)
Prefer to treat patient B	30 (60%)	22 (44%)	21 (42%)	11 (22%)	11 (22%)	12 (13%)
Total	50 (100%)	50 (100%)	50 (100%)	50 (100%)	50 (100%)	50 (100%)
	EoL vs. non-EoL	Age pref test	Time pref test	Q vs. L (30yrs)	Q vs. L (70yrs)	L, EoL vs. Q, non-EoL

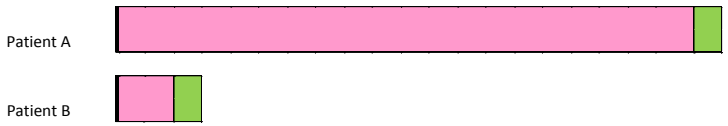
Results

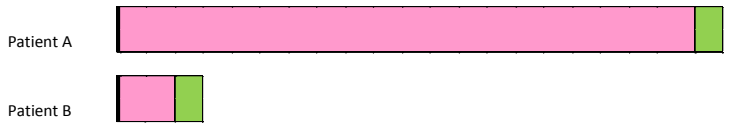


Results

- Cross-tabs particularly insightful

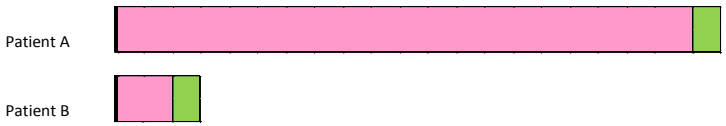
S2 / S1	Prefer A	No preference	Prefer B	Total
Prefer A	8	3	2	13
No preference	1	5	1	7
Prefer B	7	4	19	30
Total	16	12	22	50

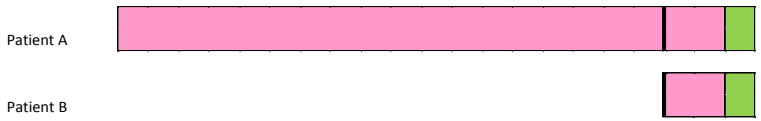




Results

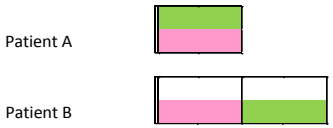
S2 \ S3	Prefer A	No preference	Prefer B	Total
Prefer A	6	3	7	16
No preference	3	5	4	12
Prefer B	7	5	10	22
Total	16	13	21	50

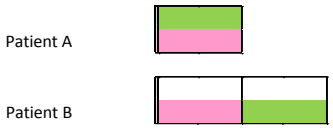




Results

S4 \ S5	Prefer A	No preference	Prefer B	Total
Prefer A	22	3	4	29
No preference	1	8	1	10
Prefer B	5	0	6	11
Total	28	11	11	50





Results

S6 S2	Prefer A	No preference	Prefer B	Total
Prefer A	10	2	4	16
No preference	6	5	1	12
Prefer B	15	0	7	22
Total	31	7	12	50

Summary of findings

- Some evidence that the majority of people wish to give higher priority to end of life patients than to non-end of life patients, although the observed result is not significant at the 5% level (p=0.08)
- No evidence that age is the motivating factor for giving higher priority to end of life patients (p=0.16)
- No evidence that time preference is the motivating factor for giving higher priority to end of life patients (p=1.00)

Summary of findings

- Strong evidence that people do not wish to give equal priority to life-extending and quality of life-improving treatments for end of life patients (p=0.00)
- No evidence that age is the motivating factor for giving higher priority to either life-extending or quality of life-improving treatments for end of life patients (p=0.97)
- Some association between the availability of quality of life-improving treatment and the propensity to choose life-extending treatment for end of life patients, although the observed result is not significant at the 5% level (p=0.06)

Summary of findings

- Nobody chose ‘BBBBBB’ or ‘BB=BBB’ (the choice sets that most closely correspond to the current NICE policy)

- Tick-box questionnaire provided useful supporting data, but the information elicited has a number of limitations:
  - 28% of respondents gave reasons that were inconsistent with their choices or that contradicted other reasons given
  - Many respondents ticked boxes referring to ‘factually correct’ statements – does not offer much insight into nature of preferences
  - Remains unclear why respondents prefer to treat the patient “who has longer left to live”

Main discussion points

- No consensus set of preferences
- Slight majority wish to give priority to the end of life patient
- Sizeable minority wish to give priority to the non-end of life patient (may be a threshold)
- 'No preference' rarely expressed
- Strong preference for quality of life-improving treatments
- People are happy to prioritise based on characteristics of patients/disease/treatment when gains to all patients are equal in size … next step is to understand the extent to which they would *sacrifice* health gain to pursue equity objectives