Scottish Government Health Directorates Chief Scientist Office

FOCUS ON RESEARCH

Establishing QALY Weights for End of Life (EQWEL)

Researchers

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Aim

Criteria used by the Scottish Medicines Consortium (SMC) and National Institute for Health and Care Excellence (NICE) to assess end-of-life (EoL) technologies mean these medicines can be provided even if there is a large opportunity cost. However, empirical evidence of public preferences is equivocal for EoL health gains and limited for the value given to different types of EoL health benefits – in the form of both quality-of-life (QoL) improvement and life-extension (LE). In this study, we examine individual and societal preferences for health gains at the EoL relative to those from non-terminal health problems (Non-EoL) and for different types of EoL health gains.

Project Outline/Methodology

Public preferences for eight scenarios were elicited using two main approaches: Person Trade-Off (PTO – societal preferences) and Willingness to Pay (WTP – individual preferences). The survey was administered via Computer Assisted Personal Interview (CAPI), between May and October 2016, to 901 participants quota sampled to reflect the Scottish population.

Key Results

PTO results indicate a preference for Non-EoL health gains over EoL health gains; WTP results are less clear but at the aggregate level suggest EoL health gains are preferred to Non-EoL health gains; and within EoL, LEs are not preferred to QoL improvements (PTO results suggest QoL improvements are preferred).

Conclusions

This study has generated new empirical evidence regarding the relative value of EoL health gains vs. Non-EoL health gains and of different types of health gains at the EoL. Results indicate no clear preference for EoL (particularly LE) health gains.

What does this study add to the field?

Studies of societal values and provision of EoL medicines at high cost have yield very mixed results. Of 17 papers reporting empirical studies of societal preferences and EoL: 7 papers find a positive premium for EoL, 7 negative and 3 report mixed findings. Issues are raised in our study that could help to explain some of these mixed results.
3 of the 4 previous studies using WTP find EoL health gains are preferred (the same as our study). However we also find our results are driven by a small group of respondents who prefer EoL health gains in WTP and, broadly, are willing to pay more than those preferring Non-EoL health gains.
One interpretation of our results is that when people value their own health (WTP) EoL gets more emphasis. However WTP questions require individuals to value one treatment at a time (A) rather than jointly (A v B) as in PTO. Also as our topic is difficult and individuals may not have well-defined preferences on the issues raised, individuals may have a range from which they are willing to pay for different treatments. These issues could, in part, explain why a discrepancy is found between PTO and WTP results.

Implications for Practice or Policy

Policies used by SMC and NICE give additional weight to EoL health gains, particularly LEs at the EoL in the case of NICE. The NICE policy was introduced on the basis of claims about societal values – that the general public values LE health gains at the EoL more than any other. However, our results suggest that there is not a clear preference for EoL (particularly LE) health gains.

Where to next?

No EoL study has used range WTP and/or joint evaluation. We plan to conduct in-depth interviews to explore whether preferences are driven by these issues. Interviews will contain a qualitative element to allow further exploration of why preferences change when elicited individually or societally.

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