

APPENDIX: DEVELOPMENT AND CONTENTS OF THE QUESTIONNAIRE

The study-specific questionnaire was developed by the researchers behind the study following a literature review that showed that there were no existing instruments addressing the issues under study. However, 2 of the questions were informed by existing questionnaires. The first of these on perceptions of meetings with physicians and nurses in health care drew on a questionnaire by Davis *et al.*¹⁷ Their questionnaire was modified somewhat so that the questions focused on the patient's own experiences of meetings in general with physicians and nurses, instead of asking about specific hypothetical situations in health care, as in Davis *et al.*¹⁷ Further, the question on the respondent's beliefs concerning patients' potential to make contributions to safer health care was inspired by questions in the World Health Organization's surgical safety checklist.²⁰ However, the World Health Organization questionnaire was modified to feature topics relevant for patient involvement in patient safety highlighted by health care professionals in previous Swedish studies.^{21 22}

The final questionnaire consisted of 14 questions, of which 13 were closed-ended and 1 was open-ended. Eleven questions were analysed for this study. The first 6 questions concern the respondent's socio-demography: age; sex; education level; occupation; latest visit to health care; and health status, which was assessed with a single SF-1 question,²³ derived from the Short Form Health Survey 36 (SF-36) instrument.^{24 25}

Two questions concerned the respondent's perceptions of encounters with physicians (consisting of 3 sub-questions) and with nurses (3 sub-questions) in health care ("How do you usually experience your meetings with physicians/nurses in health care?"). The questions addressed 3 aspects of such encounters, asking the respondent to assess how difficult or easy it is to ask a physician and nurse "questions to get information about my illness or treatment", tell a physician and nurse "if I recognize something that seems odd (or is difficult to

understand) in my treatment or care”, and tell a physician and nurse “if she/he makes a mistake”. The response options were on a 4-point Likert scale: “very easy”; “quite easy”; “quite difficult”; “very difficult”. Further, the option “no opinion” was available.

The respondent’s beliefs concerning patients’ potential to make contributions to making health care safer are addressed in 1 question (6 sub-questions). The questions concern the extent to which the respondent believes patients can contribute to making health care safer, that patients who ask questions can contribute to safer health care, that patients who ask questions risk receiving worse care than other patients, that it is easier for patients to ask questions if they are encouraged to do so by the health care professionals, that patients who notify health care professionals about shortcomings in their care or treatment risk getting worse care than other patients, and that patients have a responsibility to point out shortcomings in their care or treatment that the health care professionals do not recognize. The response options were on a 4-point Likert scale: “agree completely”; “agree to a large extent”; “agree to some extent”; “do not agree”.

One question concerned whether the respondent has suffered harm in health care during the latest 10 years. Those who responded “yes” to this question were also asked to choose 1 of 3 options: did they believe the harm “could have been avoided” if health care professionals had listened to them, “could possibly have been avoided” if health care professionals had listened to them or if the harm “could not have been avoided” even if health care professionals had listened to them. Respondents were asked to report on the perceived avoidability of harm related to the last experience of harm if they had had more than one harm episode in the last 10 years.