



**A Novel Decision Aid to Help Plan for Serious Illness:  
Results of a multi-site randomized trial**

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| More Detailed Keywords:       | End of Life, Values, Preferences, Decision Aids, Decision Making   |
| Keywords:                     | Critical care, intensive care  |
| Abstract:                     | <p>Background: Purpose of this study was to evaluate the efficacy of a novel decision support intervention, the Plan Well Guide™ in increasing Goals of Care Determinations (GCD) and decisional outcomes.</p> <p>Methods: We conducted a randomized trial in 3 primary care practices in Canada. Recruited 120 "high-risk patients" referred by the primary care doctor to require establishment or review of their GCD. Enrolled patients were randomized to receive the Plan Well Guide™ delivered by trained facilitator or usual care.</p> <p>Results: From 2017-2018, 123 patients were randomized, 119 completed the trial. The average age of patients was 74 years. Post intervention, GCD completion rates in intervention and usual care patients were 95% versus 91% (risk difference [RD]=4% [95% CI, -14% to 22%], p=0.47) and concordance rates between medical orders and expressed preferences were 78% versus 66%, (RD=12% [95% CI, -7% to 30%] p=0.20). Significantly fewer intervention patients were written medical orders for ICU and CPR (34 % vs. 60%, RD=-26% [-42% to -8%], p=0.006) compared to usual care. Patients in the intervention group had lower decisional conflict scores. Physicians considered intervention patients to have lower decisional conflict (10.4±11.7 vs. 14.9±16.9 RD=-4.7 [-9.9 to 0.4], p=0.07) spent less time with them (9.7 vs 13.2 mins, diff=-3.5 [-5.5 to -1.5 mins] p&lt;0.001) compared to usual care patients.</p> <p>Interpretation: The decision support intervention did not increase completion rates of GCD but did seem to improve some aspects of decisional quality while reducing the physician's time to accomplish GCD decisions.</p> <p>Trial Registration: Clinicaltrials.gov NCT03434626</p> |

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## CONSORT 2010 checklist of information to include when reporting a randomised trial\*

| Section/Topic                    | Item No | Checklist item  | Reported on page No |
|----------------------------------|---------|---|---------------------|
| <b>Title and abstract</b>        |         |   |                     |
|                                  | 1a      | Identification as a randomised trial in the title   | 1                   |
|                                  | 1b      | Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)   | 2                   |
| <b>Introduction</b>              |         |   |                     |
| Background and objectives        | 2a      | Scientific background and explanation of rationale  | 3                   |
|                                  | 2b      | Specific objectives or hypotheses   | 3                   |
| <b>Methods</b>                   |         |   |                     |
| Trial design                     | 3a      | Description of trial design (such as parallel, factorial) including allocation ratio  | 3,4                 |
|                                  | 3b      | Important changes to methods after trial commencement (such as eligibility criteria), with reasons  | n/a                 |
| Participants                     | 4a      | Eligibility criteria for participants   | 4                   |
|                                  | 4b      | Settings and locations where the data were collected  | 4                   |
| Interventions                    | 5       | The interventions for each group with sufficient details to allow replication, including how and when they were actually administered   | 4,5                 |
| Outcomes                         | 6a      | Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed  | 5                   |
|                                  | 6b      | Any changes to trial outcomes after the trial commenced, with reasons   | n/a                 |
| Sample size                      | 7a      | How sample size was determined  | 5,6                 |
|                                  | 7b      | When applicable, explanation of any interim analyses and stopping guidelines  | n/a                 |
| <b>Randomisation:</b>            |         |   |                     |
| Sequence generation              | 8a      | Method used to generate the random allocation sequence  | 4                   |
|                                  | 8b      | Type of randomisation; details of any restriction (such as blocking and block size)   | 4                   |
| Allocation concealment mechanism | 9       | Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned | 4                   |
| Implementation                   | 10      | Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions   | 4                   |
| Blinding                         | 11a     | If done, who was blinded after assignment to interventions (for example, participants, care providers, those  | 5                   |

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|--|-----|---|------|
|  |     | assessing outcomes) and how   |      |
|  | 11b | If relevant, description of the similarity of interventions   | n/a  |
| Statistical methods                                  | 12a | Statistical methods used to compare groups for primary and secondary outcomes   | 6    |
|  | 12b | Methods for additional analyses, such as subgroup analyses and adjusted analyses  | n/a  |
| <b>Results</b>                                       |     |   |      |
| Participant flow (a diagram is strongly recommended) | 13a | For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome    | 7    |
|  | 13b | For each group, losses and exclusions after randomisation, together with reasons  | 7,8  |
| Recruitment  | 14a | Dates defining the periods of recruitment and follow-up   | 7    |
|  | 14b | Why the trial ended or was stopped  | n/a  |
| Baseline data  | 15  | A table showing baseline demographic and clinical characteristics for each group  | 24   |
| Numbers analysed                                     | 16  | For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups           | 7,8  |
| Outcomes and estimation                              | 17a | For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval) | 7,8  |
|  | 17b | For binary outcomes, presentation of both absolute and relative effect sizes is recommended   | 7,8  |
| Ancillary analyses                                   | 18  | Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory         | n/a  |
| Harms  | 19  | All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)   | n/a  |
| <b>Discussion</b>                                    |     |   |      |
| Limitations  | 20  | Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses                                  | 10   |
| Generalisability                                     | 21  | Generalisability (external validity, applicability) of the trial findings   | 8-10 |
| Interpretation                                       | 22  | Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence                                     | 8-10 |
| <b>Other information</b>                             |     |   |      |
| Registration   | 23  | Registration number and name of trial registry  | 2    |
| Protocol   | 24  | Where the full trial protocol can be accessed, if available   | n/a  |
| Funding  | 25  | Sources of funding and other support (such as supply of drugs), role of funders   | 11   |

\*We strongly recommend reading this statement in conjunction with the CONSORT 2010 Explanation and Elaboration for important clarifications on all the items. If relevant, we also recommend reading CONSORT extensions for cluster randomised trials, non-inferiority and equivalence trials, non-pharmacological treatments, herbal interventions, and pragmatic trials. Additional extensions are forthcoming: for those and for up to date references relevant to this checklist, see [www.consort-statement.org](http://www.consort-statement.org).

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**A Novel Decision Aid to Help Plan for Serious Illness:  
Results of a multi-site randomized trial**

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**for the Canadian Researchers at the End of Life Network (CARENET)**

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Keywords: End of life, values, preferences, decision aids, critical care, decision making, ethics

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Word Count: 2500

## ABSTRACT

**Background:** Purpose of this study was to evaluate the efficacy of a novel decision support intervention, the Plan Well Guide™ in increasing Goals of Care Determinations (GCD) and decisional outcomes.

**Methods:** We conducted a randomized trial in 3 primary care practices in Canada. Recruited 120 “high-risk patients” referred by the primary care doctor to require establishment or review of their GCD. Enrolled patients were randomized to receive the Plan Well Guide™ delivered by a trained facilitator or usual care.

**Results:** From 2017-2018, 123 patients were randomized and 119 completed the trial. The average age of patients was 74 years. Post intervention, GCD completion rates in intervention and usual care patients were 95% versus 91% (risk difference [RD]=4% [95% CI, -14% to 22%], p=0.47) and concordance rates between medical orders and expressed preferences were 78% versus 66%, (RD=12% [95% CI, -7% to 30%] p=0.20). Significantly fewer intervention patients were written medical orders for ICU and CPR (34 % vs. 60%, RD=-26% [-42% to -8%], p=0.006) compared to usual care. Patients in the intervention group had lower decisional conflict scores. Physicians considered intervention patients to have lower decisional conflict (10.4±11.7 vs. 14.9±16.9 RD=-4.7 [-9.9 to 0.4], p=0.07) and spent less time with them (9.7 vs 13.2 mins, diff=-3.5 [-5.5 to -1.5 mins] p<0.001) compared to usual care patients.

**Interpretation:** The decision support intervention did not increase completion rates of GCD but did seem to improve some aspects of decisional quality while reducing the physician’s time to accomplish GCD decisions.

**Trial Registration:** Clinicaltrials.gov NCT03434626

**Abstract Words: 250**

## 1. Introduction

Several recent studies continue to describe significant deficiencies in the quality or quantity (or both) of communication and decision-making during serious illness.<sup>1,2,3,4,5,6</sup> A major problem is that doctors infrequently engage in such conversations with seriously ill patients because they believe they are ill-prepared to have such conversations.<sup>7,8</sup> Other research conducted by our group found considerable discordance between older patients' stated values and their preferences related to the use of life-sustaining treatments and a considerable lack of knowledge and understanding regarding cardiopulmonary resuscitation, a key medical decision for hospitalized patients.<sup>9,10,11</sup> We concluded that more efforts to increase the 'decisional readiness' of seriously ill patients (and their families) were warranted before we can expect health care professionals to engage them in high quality conversations that will improve clinical decision-making in the context of serious illness.

Accordingly, we developed a novel decision aid, the Plan Well Guide™, with the express aim of helping patients clarify their authentic values and be truly informed about the medical treatment options in the context of serious illness. We aimed to evaluate its efficacy in primary care settings, before the onset of serious illness. Our overarching hypothesis was that the use of this decision aid in older patients in primary care, compared to usual care, will result in increased quantity and quality of subsequent planning decisions with primary care physicians.

## 2. Methods

This was a prospective multi-center, patient-based, pragmatic, assessor-blinded, parallel group, randomized clinical trial, conducted from September 2017 to October 2018. The project was approved by the Hamilton Integrated Research Ethics Board and written informed consent was obtained from all patients and verbal consent from participating Physicians. We partnered with 3

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3 non-academic primary care settings in Lethbridge, Alberta, Canada. In Alberta, a province-wide  
4 standard medical order form, Goals of Care Designation (GCD), is used for physicians to indicate the  
5 level of care a patient is to receive when seriously ill (resuscitative or intensive care, medical care, or  
6 comfort care). We aimed to enroll 120 “high-risk patients” considered by the primary care Physician  
7 to require establishment or review of this GCD form due to a perceived high probability of  
8 hospitalization. Patients who did not speak English were excluded from this trial. Participating  
9 doctors referred potentially eligible patients to the GCD clinic and provided a workbook on advance  
10 care planning (ACP, Speak Up Workbook) with encouragement to complete the workbook prior to  
11 their GCD clinic appointment. At that appointment, the GCD Facilitator explained the nature of the  
12 trial, randomized consenting patients and collected basic demographic data.  
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26 Our randomization process used sequentially numbered, opaque sealed envelopes prepared by  
27 a biostatistician otherwise uninvolved in study managed or patient recruitment. Patients were  
28 randomly allocated (1:1) to receive the decision support intervention or usual care. Randomization  
29 used permuted blocks of previously undiscussed varying size of 2, 4 and 8 stratified by Facilitator.  
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35 The process to develop and initially evaluate the Plan Well Guide™ decision support  
36 intervention is described in more detail in Appendix 1. To deploy the intervention in this trial, we  
37 created a PowerPoint presentation with audio explanations of the content to enable a structured and  
38 consistent delivery of the material to participating patients. All facilitators participated in face-to-face  
39 training led by the principal investigator (PI). For patients randomized to the intervention group, the  
40 Facilitator walked the patient through the Plan Well Guide™ presentation and at the end of this  
41 presentation, the Facilitator worked with the patient to fill out the ‘Dear Doctor’ letter (eFigure 3)  
42 and coached the patient to communicate their values and preferences to the referring doctor via this  
43 letter. The patient was then referred back to their family doctor for review of the Dear Doctor letter  
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3 and finalization of the GCD. At this point, the participating doctor filled out the physician assessment  
4 form that elicited their perceptions of effect of the intervention on the patient.  
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8 If the patient was randomized to usual care, after filling out baseline forms, the Facilitator  
9 instructed the patient to return to see the referring doctor to finalize the formal GCD forms. No  
10 supplementary information was provided to prepare the patient for the conversation with the doctor  
11 about GCD. After seeing a patient to establish GCD from either group, the physician completed an  
12 assessment of the encounter and returned it to the Facilitator.  
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19 The primary outcome was the proportion of patients who had a completed and signed GCD  
20 form in the patient chart 8-12 weeks post intervention. Secondary outcomes included the nature of  
21 those medical orders and the extent to which that order was consistent with their expressed  
22 preferences (Concordance measure), a short Decisional Conflict score (relating to the patient's  
23 preference for life-sustaining treatments) modified for the context of serious illness  
24 decision-making<sup>12</sup>; global rating of satisfaction with decision-making; physician ratings of the  
25 patient's Decisional Conflict; and physician time spent with patient obtaining GCD.  
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35 Eight to twelve weeks following randomization, a blinded research assistant (RA) from the  
36 Clinical Evaluation Research Unit at the Kingston General Hospital (research unit of the PI)  
37 contacted the patients in both groups to do a final outcome assessment via telephone. During the  
38 same time period, clinic charts were audited to determine the presence and content of GCD in the  
39 patient's chart.  
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#### 49 *Sample Size Justification*

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51 GCD completion rates in the average family practice setting are low (<10%).<sup>13</sup> However,  
52 given these are select patients referred to an GCD consultation clinic, we expected the completion  
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3 rate in the control group to be much higher. In order to achieve 80% power to detect a 25%  
4 improvement from 60% to 85% or a 20% improvement from 75% to 95% using a Fisher's exact test  
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6 at a two-sided  $\alpha=0.05$ , we would need follow-up assessments on 55 patients per arm. We aimed  
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8 to enrol a total of 120 patients to allow for some loss to follow-up or imbalance between arms.  
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### 10 11 12 *Statistical Analysis* 13

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15 Patient characteristics and outcomes described above were determined by group using  
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17 descriptive statistics (counts and percentage or mean and standard deviations and quartiles for highly  
18  
19 skewed variables). When calculating agreement between preferences and documented goals of care,  
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21 we omitted patients with missing data or who expressed uncertainty about their preference regarding  
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23 goals of care. Additionally, we reported concordance rates as the percentage of patients whose  
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25 preferences to receive or not to receive CPR elicited during interview, were consistent with their  
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27 documented preference for CPR on their GCD forms in their charts.  
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31 Between group differences of binary outcomes including completion of GCD forms, desired  
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33 goals of care, and agreement between preferences and documented goals of care (Concordance  
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35 measure) were tested by Fisher's exact test and described using risk differences with exact 95%  
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37 confidence intervals. We used the exact Cochran-Armitage test for trend to compare the ordinal  
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39 decisional conflict items between groups. Finally, for all continuous items including the overall  
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41 decisional conflict score and time spent with patients finalizing goals of care, we used a 2-way  
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43 ANOVA to compare the mean differences between groups while controlling for site. The analysis  
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45 was performed in SAS version 9.4 (SAS Institute Inc, Cary, NC). No adjustment was made for  
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47 multiplicity of outcomes.  
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### 3.0 Results

From September 2017 to October 2018, 163 patients were referred to this trial, 123 were consented and randomized (Figure 1). Eighty percent of patients were married, 52% were male with an average age of 74 years. There were no important differences in baseline characteristics between the 2 groups (Table 1).

Following the baseline and intervention visits, 121 of 123 returned to see their referring Physician to discuss and complete a GCD form (see Table 2). Compared to usual care patients, intervention patients were rated by their physician as having lower decisional conflict (mean  $\pm$  standard deviation decisional conflict scores in intervention versus usual care groups  $10.4 \pm 11.7$  versus  $14.9 \pm 16.9$ ; mean difference  $-4.7$  [95% Confidence Interval (CI),  $-9.9$  to  $0.4$ ],  $p=0.07$ ). The items that comprise the decisional conflict score consistently favoured the intervention group, although only clarity about which risks and benefits matter most to the patient reached statistical significance ( $p=0.03$ ) and there were trends towards improved knowledge ( $p=0.11$ ) and enough information and support from the medical team ( $p=0.13$ ). Physicians spent an average of 3.5 (95% CI: 1.5 to 5.5,  $p<0.001$ ) minutes less finalizing GCD for intervention patients compared to usual care patients (Table 2). Physicians rated their satisfaction with the clinical encounter as ‘completely’ or ‘somewhat satisfied’ in 86% of cases.

At 8-12 weeks following randomization, 4 patients could not be contacted (2 in each group); 119 were included in the final analysis (see Table 3). Completion of GCD forms were higher than expected in both groups and rates were not different between groups (95% in intervention vs. 91% in usual care, risk difference [RD]=4% [95% CI:  $-14\%$  to  $22\%$ ],  $p=0.47$ ). However, fewer intervention patients had a GCD that would lead to provision of CPR and ICU care (34 % vs. 60%, RD= $-26\%$ , 95% CI:  $-42\%$  to  $-8\%$ ,  $p=0.006$ ). Post intervention crude agreement between the medical order

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3 recorded in the GCD form and the patient's expressed preference from the interview was higher in  
4 the intervention group but differences were not statistically significant (56% vs 46% , RD=10%,  
5 95% CI: -9% to 28%, p=0.34) as was concordance between ordered care and patient wishes to  
6 receive or not to receive CPR (78% vs 66%, RD=12%, 95% CI:-7% to 30%, p=0.20). Patients in the  
7 intervention group reported lower decisional conflict compared to usual care patients, with  
8 differences being statistically significant (p<0.05) for: 1) knowing more about various treatment  
9 options, 2) having more support and information from their doctor, and 3) feeling more sure that their  
10 selected option is best for them (see item 12 Table 3). Seventy-two percent of patients were very  
11 satisfied with the decision support intervention and 86% of patients said they would definitely or  
12 probably recommend the program to others (Table 3).  
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#### 26 **4.0 Discussion**

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28 Recognizing that there was an unmet need to better prepare patients and their families to  
29 make medical treatment decisions when seriously ill, we conducted the first ever reported  
30 randomized trial in non-academic primary care settings of a novel advance medical care planning  
31 decision aid. We evaluated our novel decision support intervention on metrics related to decisional  
32 quantity and quality. Completion rates of GCD were high in both groups and not different from  
33 each other. Nevertheless, compared to usual care, we observed that this decision support intervention  
34 reduced orders for ICU care and CPR, reduced decision conflict, increased patient knowledge of  
35 medical decisions, helped clarify their values and gave them increased confidence in engaging health  
36 care professionals about their GCD. At the same time, physicians were satisfied with the decision-  
37 making process and spent less time with patients that had received the decision support intervention.  
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51 Our trial is consistent with other recent randomized trials of patient decision support tools or  
52 ACP interventions that have demonstrated that these planning or preparing interventions impact  
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3 patient and health system outcomes.<sup>14,15,16,17,18,19</sup> However, prior studies were conducted in hospital<sup>17</sup>,  
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5 academic outpatient settings<sup>18,19</sup>, or were internet-based.<sup>16</sup> In an attempt to broaden the  
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7 generalizability of these prior studies and influence care prior to onset of serious illness, we worked  
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9 in non-academic primary care settings to conduct this practice-based research. While there are many  
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11 existing ACP tools available, there are several features of our novel decision support intervention  
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13 that makes it considerably different from existing tools (see Table 4). First, as explained in the  
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15 developmental process described in the Appendix, patients have difficulty discriminating between  
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17 planning for terminal care compared to planning for medical care when seriously ill and our decision  
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19 support intervention specifically addresses these differences, unlike other ACP tools. Second, one of  
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21 the other key observations from the development process was the difficulty patients had linking their  
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23 underlying values to their preferences for medical treatments. Accordingly, we developed a short  
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25 values clarification tool that made the trade-offs between common end of life values very transparent  
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27 and then connected the values scales to the grids shown in the figures to make this process  
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29 transparent. Some argue that clinicians should only elicit ‘goals of care’ in terms that are meaningful  
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31 to the patient, which are a reflection of their personal values and priorities, such as to remain alive to  
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33 a daughter’s wedding or to remain independent.<sup>20</sup> Whilst these impressions may be helpful in  
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35 decision-making, many clinicians then translate these broad, patient-centered statements into specific  
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37 medical decisions about which treatments to use or not to use in the context of serious illness without  
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39 further patient input.<sup>21</sup> Such an approach may be biased, lacks transparency, reliability, and in our  
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41 view, perpetuates a power imbalance that may be a major barrier to shared decision-making  
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43 approaches.<sup>22,23,24,25,26</sup> What is unique about Plan Well Guide™ is that it explains decision-making  
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45 in the context of serious illness, helps patients clarify their authentic values using constrained values  
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47 clarification approaches, educates patients about the different levels of medical care available when  
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3 seriously ill and then *transparently* connects patient values to treatment preferences.  
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6 In a hospitalized population, we have previously reported low rates of agreement between  
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8 patients' expressed preferences and their goals of care documented in the medical chart with the  
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10 majority of the medical error related to the overuse of CPR. **Error! Bookmark not defined.** We observed that  
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12 patients in the intervention group were much less likely to express a preference for CPR. Along with  
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14 the fact that the decision support intervention reduced physician time involvement in decision-  
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16 making, the intervention may have important economic implications.  
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20 The strengths of this project include the rigor with which the decision aid was developed and  
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22 evaluated (See supplementary appendix), concealed randomized, blinded patient-outcome assessment  
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24 and limited loss of follow up. A limitation of this trial is the small sample which resulted in limited  
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26 power for many of the outcome comparisons. Moreover, the small sample from a limited geographic  
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28 area limits the generalizability of the findings. Furthermore, the presence of a completed and signed  
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30 GCD form in the patient chart was much higher than expected in the control arm leaving little room  
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32 for improvement from the intervention. Perhaps, clinicians only referred patients motivated to engage  
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34 in ACP/GCD conversations or, the nature of the study design with a protocolized follow up  
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36 assessment explains these findings. Also, all study patients received ACP materials which may have  
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38 further motivated them to complete their GCD. These factors likely combine to minimize the impact  
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40 of the intervention and call into question the potential effect of the intervention in a broader,  
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42 unselected population with less rigorous follow up. Nevertheless, we observed enough of a signal in  
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44 this first trial to suggest that further research is warranted. Although to date this decision aid has  
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46 been implemented with trained, expert facilitators, we are actively developing a web-based version  
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48 of the tool where a patient can walk through the materials independent of a facilitator (See  
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50 [www.planwellguide.com](http://www.planwellguide.com)).  
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## 4.2 Conclusions

The decision support intervention had no impact on rates of completion of GCD in primary care. However, it seemed to help patients clarify values, better inform them regarding the medical treatment options available when seriously ill and may reduce their preference for resuscitation. This decision-support intervention reduces physician barriers to engaging their patients by reducing the time cost of having these important discussions. This decision support intervention has the potential to improve the quality and quantity of GCD discussions and reduce health care costs. We conclude that further evaluation in patients making the treatment decisions in a broader population and more diverse settings with a longer follow-up is warranted.

## Acknowledgements

DKH and RDH were involved in data collection and had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

All authors contributed to the conception and design of the study and to the drafting of the article. All authors contributed to the analysis and interpretation of data, revised the article for important intellectual content, and gave final approval of the version to be published.

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Competing Interest: None to declare.

## Appendix 1

### The Development and Initial Evaluation of Plan Well Guide™

Decision aids are tools developed and promoted to increase high quality decisions in health care. These tools typically enhance communication about treatment options, and the benefits, harms, and outcomes associated with each option, in a manner that is easily understood by lay persons. Cardona-Morell and colleagues performed a systematic review of decision aids to help older patients facing serious illness and found 17 relevant studies (6 RCTs and 11 observational studies).<sup>27</sup> Compared to usual care, satisfaction with or acceptability of the decision process or the decision made was high regardless of the type of decision aid. The review also demonstrated that decision aids increased patient knowledge (but the improvement was small and absent in many trials), reduced decision conflict (but not consistently in all studies), and in a few trials, improved decision concordance between patients and their surrogates after exposure to a decision aid. In five studies, the decision aids included a values clarification process but only one made the trade-offs inherent in values clarification explicit. None explicated the difference between resuscitative/intensive care versus medical care versus comfort care. Together, these results suggest that the published decision aids to date may be lacking in their ability to help with the types of decisions that are most relevant to older individuals with serious illness.

Accordingly, we set out to develop a novel decision aid to support older patients prepare for serious illness. In developing the decision aid, we were considerate of the domains and items of International Patient Decision Aid Standards (IPDAS) instrument used to assess quality of decision support tools.<sup>28</sup> To develop the content of the decision aid, we first reviewed the literature on medical decision-making in the context of serious illness and drafted a preliminary version of the decision support intervention. We then created a “Goals of Care Designation (GCD) Clinic” in a family medicine primary care setting in Lethbridge, Alberta, Canada. In Alberta, a province-wide standard



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3 medical order form is used for physicians to indicate the type of care a patient is to receive when  
4 seriously ill (resuscitative (intensive) care, medical care, or comfort care). It is the expectation of the  
5 health care system that all citizens of the province will meet with physicians to have this formed  
6 filled out in advance and will carry this form in an associated 'green sleeve' to their doctors'  
7 appointments or hospital visits. A family physician (AB) referred older patients with serious illness  
8 she expected would benefit from more in depth GCD discussions to this consultation clinic. DKH  
9 and RH met with patients to explain the context of the meeting, the decision to be made, and the  
10 various treatment options. Twenty-four patients were referred to the GCD primary care clinic and  
11 participated in the development phase of the decision aid. A description of their baseline  
12 demographic is found in eTable 1. The average age of participants was 78 years old, 37% were  
13 male, and most were in good health.

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During these consultations, there were several key learnings that lead to further refinement of the decision support intervention. First, we realized that patients were having difficulty discriminating between planning for terminal care compared to planning for medical care when seriously ill. In our observations, the majority of patients just wanted to be kept comfortable when it was certain they were dying (condition of certainty). One of our concerns is that, to the extent that these patients misunderstood the context of the question about serious illness, they could be expressing a treatment preference that would result in their certain death when they could have recovered with simple curative treatments or intensive care, when appropriate. Accordingly, we created language strategies to help people understand the differences between terminal care and serious illness. However, when we explained that we were planning for serious illness where there was a probability of death but also, a probability that they may survive, they further struggled to express a treatment preference without knowing what the clinical outcome would be (condition of

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3 uncertainty). This required us to develop additional materials to explicitly define serious illness and  
4 the outcomes associated with it and to explain that the goal of the discussion was to express a  
5 preference that would best capture the person's wishes at the present time, under conditions of  
6 'uncertainty' about whether a sudden serious illness requiring hospitalization would be terminal or  
7 not. We likened this to listening to a weather report from a meteorologist where there is a certain  
8 probability of rain and, without knowing for sure whether it would rain or not, the person still had to  
9 decide whether they would go out and whether to bring an umbrella.  
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19 Second, we further observed that patients had difficulty expressing their values in a way that  
20 informed future medical decisions. Since the treatment options are preference sensitive and  
21 preferences should be aligned with values, we then developed a short values clarification tool that  
22 included an explanation of values and their relationship to treatment decisions and gave examples of  
23 different end-of-life (EOL) values (adapted from Scheunemann et. al<sup>29</sup>). We further explained how  
24 certain values compete or conflict with each other, and patients were asked to rate on 7-point Likert-  
25 type scales 1) the degree to which quality of life was more or less important to them compared to  
26 quantity of life and 2) whether a natural death vs. a machine-supported death was more important  
27 (see eFigure 1 for examples of these scales). To aid in clinical decision-making and to make the  
28 linkage between values and preferences more explicit, we developed a system of grids that used the  
29 ratings of importance on the values questions to indicate which treatment option may be preferred  
30 (see eFigure 2). These treatment options were then described in more detail with information about  
31 the nature, location, harms, benefits and associated outcomes of the different treatment options  
32 provided in text and with visual images. Once the benefits and risks or harms of intensive care were  
33 explained, another set of value statements and associated grids was presented. Patients were then  
34 asked to rate their willingness to accept the risks of ICU care and their willingness to remain alive  
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3 but in a potentially reduced health or functional state (See eFigure 1). The highlighted treatment  
4 options on the grid were not considered the definitive answer but rather, the grids were used to  
5 provide structured guidance to the patient helping them link their stated values to reasonable  
6 treatment preferences. Where there were discordant treatment preferences highlighted on the grids  
7 (for example, the first grid suggested the preferred medical option was comfort care and the second  
8 grid indicated medical care), it led to a deeper conversation about why the discordance existed, the  
9 patient's values, and which values were most important, were further clarified. The final step of this  
10 consultation was to elicit a treatment preference for the use of life-sustaining treatments. To do so,  
11 we used a taxonomy describing different levels of the use or non-use of life-sustaining treatments  
12 (eTable 3 in supplementary appendix). This taxonomy was developed with input from medical  
13 experts and has been used extensively in our prior research.<sup>1,Error! Bookmark not defined.,9</sup> Based on  
14 responses to values and initial grids (preferences), it was determined whether CPR is relevant and if  
15 so, patients watched a brief CPR video decision aid that is publicly available in the Plan Well guide  
16 Website. For patients preferring comfort care, this step was skipped.

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19 Finally, to enable communication between the patient/facilitator interaction and the referring  
20 physician, we developed a standardized "Dear Doctor" letter that records the nature of the  
21 conversation, the stated values and expressed treatment preferences. This letter gave patients a  
22 written record of their 'talking points' with the doctor and our hypothesis was that this 'informed and  
23 capacitated' patient would be able to significantly influence medical decision-making to ensure that  
24 their stated treatment preferences are formally recorded on the goals of care documents and that the  
25 care they actually receive is more likely to be consistent with their authentic value structure.

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28 When a near-final version of the decision support intervention was ready, we created a  
29 powerpoint presentation that included all the content of the decision aid. We then held a series of  
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3 focus groups and one-on-one interviews with 42 health care professionals with expertise in critical  
4 care medicine, nursing, geriatrics, family medicine, and palliative care, to obtain their input on the  
5 decision aid. The majority of the input focused on expanding the range of possible outcomes  
6 associated with intensive care treatments; hence, more information is presented on intensive care  
7 relative to medical and comfort care. Further revisions were made and then the tool was evaluated by  
8 a group of lay patient and family advisors in Ontario and Alberta. We recruited 18 lay persons to  
9 participate in 2 hour face-to-face session in Kingston Ontario or a 2 hour webinar where the  
10 intervention was presented and a formal evaluation sought from participants. This evaluation  
11 instrument used in this project was informed by the framework for evaluation of sensibility  
12 developed by Feinstein<sup>30</sup> and adapted questions from a variety of other sources that have measured  
13 similar constructs.<sup>31,32</sup> In essence, we asked participants the questions with associated response  
14 options in eTable 2.

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31 Eighteen lay people participated in the final evaluation (see eTable 1). Overall, on a scale of  
32 1=poor and 5=very good, participants rated the tool a median of 5 (range 3-5). The majority found  
33 the language clear and understandable, was easy to work through, felt the amount of information was  
34 “just right”, and thought the decision support tool would be very helpful to patients with serious  
35 illness. When asked if they would use it if recommended by their doctor, the median response was  
36 “definitely would use it.” In addition, the majority also responded that they would recommend it to  
37 others (see eTable 2).  
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51 **eFigure 3 An Example of a Dear Doctor Letter (see attached pdf)**  
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**Table 1 – Patient Characteristics**

|  | <b>Intervention<br/>(n=66)</b> | <b>Usual Care<br/>(n=57)</b> | <b>Overall<br/>(n=123)</b> |
|--|--------------------------------|------------------------------|----------------------------|
| <b>Demographics</b>  |                                |                              |                            |
| <b>Age</b> (mean±standard deviation)   | 73.5±15.9                      | 74.4±11.1                    | 73.9±13.9                  |
| <b>Sex</b>   |                                |                              |                            |
| <i>Male</i>  | 33 (50.0%)                     | 31 (54.4%)                   | 64 (52.0%)                 |
| <i>Female</i>  | 33 (50.0%)                     | 26 (45.6%)                   | 59 (48.0%)                 |
| <b>Current marital status</b>  |                                |                              |                            |
| <i>Married or living as married</i>  | 54 (81.8%)                     | 44 (77.2%)                   | 98 (79.7%)                 |
| <i>Widowed</i>   | 9 (13.6%)                      | 8 (14.0%)                    | 17 (13.8%)                 |
| <i>Never married</i>   | 2 (3.0%)                       | 4 (7.0%)                     | 6 (4.9%)                   |
| <i>Divorced or separated; not remarried</i>  | 1 (1.5%)                       | 1 (1.8%)                     | 2 (1.6%)                   |
| <b>Highest level of education completed</b>  |                                |                              |                            |
| <i>Did not complete secondary school or high school</i>  | 18 (27.3%)                     | 10 (17.5%)                   | 28 (22.8%)                 |
| <i>Completed secondary or high school</i>  | 7 (10.6%)                      | 9 (15.8%)                    | 16 (13.0%)                 |
| <i>Had some university education or completed a community college, technical college, or post-secondary program (for example; trade, technical or vocational school)</i> | 25 (37.9%)                     | 27 (47.4%)                   | 52 (42.3%)                 |
| <i>University degree (for example; BA, BSc, BSN)</i>   | 12 (18.2%)                     | 5 (8.8%)                     | 17 (13.8%)                 |
| <i>Graduate degree (for example; MD, DDS, DMD, DVM, OD, Master's, or PhD)</i>  | 4 (6.1%)                       | 6 (10.5%)                    | 10 (8.1%)                  |
| <b>In general, how would you rate your overall quality of life</b>   |                                |                              |                            |
| <i>Excellent</i>   | 8 (12.1%)                      | 8 (14.0%)                    | 16 (13.0%)                 |
| <i>Very Good</i>   | 29 (43.9%)                     | 32 (56.1%)                   | 61 (49.6%)                 |
| <i>Good</i>  | 22 (33.3%)                     | 12 (21.1%)                   | 34 (27.6%)                 |
| <i>Fair</i>  | 6 (9.1%)                       | 3 (5.3%)                     | 9 (7.3%)                   |
| <i>Poor</i>  | 1 (1.5%)                       | 2 (3.5%)                     | 3 (2.4%)                   |
| <b>How often do you need someone to help you when you read instructions, pamphlets or other written material from your doctor</b>  |                                |                              |                            |
| <i>Never</i>   | 36 (54.5%)                     | 32 (56.1%)                   | 68 (55.3%)                 |
| <i>Occasionally</i>  | 20 (30.3%)                     | 16 (28.1%)                   | 36 (29.3%)                 |
| <i>Sometimes</i>   | 7 (10.6%)                      | 3 (5.3%)                     | 10 (8.1%)                  |
| <i>Often</i>   | 1 (1.5%)                       | 3 (5.3%)                     | 4 (3.3%)                   |
| <i>Always</i>  | 2 (3.0%)                       | 3 (5.3%)                     | 5 (4.1%)                   |

**Table 2. Follow Up Physician Visit-Physician Assessment**

|  | Intervention<br>Physician visit<br>(n=66) | Usual Care<br>Physician visit<br>(n=55) | Overall<br>(n=121)      | p<br>values |
|--|---|---|-------------------------|-------------|
| <b>Decisional Conflict</b>   |   |   |                         |             |
| <b>Overall Decisional Conflict Score (0-best to 100-worst) mean±SD</b>   | 10.4±11.7                                 | 14.9±16.9                               | 12.4±14.4               | 0.07        |
| <b>Does your patient know the benefits and risks of each option</b>  |   |   |                         | 0.11        |
| Yes  | 40 (60.6%)                                | 25 (45.5%)                              | 65 (53.7%)              |             |
| Probably Yes   | 17 (25.8%)                                | 19 (34.5%)                              | 36 (29.8%)              |             |
| Unsure   | 6 (9.1%)                                  | 4 (7.3%)                                | 10 (8.3%)               |             |
| Probably No  | 1 (1.5%)                                  | 6 (10.9%)                               | 7 (5.8%)                |             |
| No   | 1 (1.5%)                                  | 0 (0.0%)                                | 1 (0.8%)                |             |
| Missing/ Declined  | 1 (1.5%)                                  | 1 (1.8%)                                | 2 (1.7%)                |             |
| <b>Is the patient clear about which benefits and risks matter most to them?</b>                                      |   |   |                         | 0.03        |
| Yes  | 40 (60.6%)                                | 27 (49.1%)                              | 67 (55.4%)              |             |
| Probably Yes   | 23 (34.8%)                                | 15 (27.3%)                              | 38 (31.4%)              |             |
| Unsure   | 3 (4.5%)                                  | 9 (16.4%)                               | 12 (9.9%)               |             |
| Probably No  | 0 (0.0%)                                  | 2 (3.6%)                                | 2 (1.7%)                |             |
| Missing/ Declined  | 0 (0.0%)                                  | 2 (3.6%)                                | 2 (1.7%)                |             |
| <b>Does the patient have enough support and advice from their family to make a choice</b>                            |   |   |                         | 0.39        |
| Yes  | 50 (75.8%)                                | 37 (67.3%)                              | 87 (71.9%)              |             |
| Probably Yes   | 12 (18.2%)                                | 13 (23.6%)                              | 25 (20.7%)              |             |
| Unsure   | 4 (6.1%)                                  | 3 (5.5%)                                | 7 (5.8%)                |             |
| Probably No  | 0 (0.0%)                                  | 1 (1.8%)                                | 1 (0.8%)                |             |
| Missing/ Declined  | 0 (0.0%)                                  | 1 (1.8%)                                | 1 (0.8%)                |             |
| <b>Does the patient have enough support and information from the medical team/primary care team to make a choice</b> |   |   |                         | 0.13        |
| Yes  | 48 (72.7%)                                | 36 (65.5%)                              | 84 (69.4%)              |             |
| Probably Yes   | 17 (25.8%)                                | 11 (20.0%)                              | 28 (23.1%)              |             |
| Unsure   | 1 (1.5%)                                  | 3 (5.5%)                                | 4 (3.3%)                |             |
| Probably No  | 0 (0.0%)                                  | 3 (5.5%)                                | 3 (2.5%)                |             |
| Missing/ Declined  | 0 (0.0%)                                  | 2 (3.6%)                                | 2 (1.7%)                |             |
| <b>Does the patient feel SURE about the best choice for them</b>   |   |   |                         | 0.89        |
| Yes  | 37 (56.1%)                                | 31 (56.4%)                              | 68 (56.2%)              |             |
| Probably Yes   | 21 (31.8%)                                | 16 (29.1%)                              | 37 (30.6%)              |             |
| Unsure   | 4 (6.1%)                                  | 6 (10.9%)                               | 10 (8.3%)               |             |
| Probably No  | 1 (1.5%)                                  | 0 (0.0%)                                | 1 (0.8%)                |             |
| Missing/ Declined  | 3 (4.5%)                                  | 2 (3.6%)                                | 5 (4.1%)                |             |
| <b>Time spent with patient finalizing the Goals of Care (mins)</b>   | 9.7±5.4<br>(0.5, 25.0)                    | 13.2±5.0<br>(5.0, 30.0)                 | 11.3±5.5<br>(0.5, 30.0) | 0.0007      |
| <b>How satisfied were you with the outcome of these discussions?</b>   |   |   |                         |             |
| 1 - Completely dissatisfied  | 3 (4.5%)                                  |   |                         |             |
| 2 - Somewhat dissatisfied  | 3 (4.5%)                                  |   |                         |             |
| 3 - Neither satisfied nor dissatisfied   | 3 (4.5%)                                  |   |                         |             |
| 4 - Somewhat satisfied   | 18 (27.3%)                                |   |                         |             |
| 5 - Completely satisfied   | 39 (59.1%)                                |   |                         |             |

**Table 3. Telephone Follow up Assessment**

|  | <b>Intervention<br/>At follow-up<br/>(n=64)</b> | <b>Usual Care<br/>At follow-up<br/>(n=55)</b> | <b>Overall<br/>(n=119)</b> | <b>P<br/>values</b> |
|--|---|---|----------------------------|---------------------|
| <b>Preferences (FOLLOW-UP)</b>   |   |   |                            | 0.35                |
| <i>1. Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.</i>  | 10 (15.6%)                                      | 16 (29.1%)                                    | 26 (21.8%)                 |                     |
| <i>2. Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation (CPR).</i>   | 5 (7.8%)  | 2 (3.6%)                                      | 7 (5.9%)                   |                     |
| <i>3. Use machines only in the short term to see if I will get better but if the illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).</i> | 29 (45.3%)                                      | 19 (34.5%)                                    | 48 (40.3%)                 |                     |
| <i>4. Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.</i>  | 6 (9.4%)  | 5 (9.1%)                                      | 11 (9.2%)                  |                     |
| <i>5. Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation (CPR).</i>         | 11 (17.2%)                                      | 10 (18.2%)                                    | 21 (17.6%)                 |                     |
| <i>6. Unsure</i>   | 2 (3.1%)  | 0 (0.0%)                                      | 2 (1.7%)                   |                     |
| <i>Missing</i>   | 1 (1.6%)  | 3 (5.5%)                                      | 4 (3.4%)                   |                     |
| <b>Completeness of GCD in patient's Green Sleeve</b>   |   |   |                            | 0.47                |
| <i>Completed GCD</i>   | 61 (95.3%)                                      | 50 (90.9%)                                    | 111 (93.3%)                |                     |
| <i>Non completed GCD</i>   | 3 (4.7%)  | 5 (9.1%)                                      | 8 (6.7%)                   |                     |
| <b>11. Goal of Care on (GCD) Form in your Green Sleeve from Telephone assessment</b>   |   |   |                            | 0.03                |
| <i>Intensive Care including CPR</i>  | 22 (34.4%)                                      | 33 (60.0%)                                    | 55 (46.2%)                 |                     |
| <i>Intensive Care excluding CPR</i>  | 21 (32.8%)                                      | 10 (18.2%)                                    | 31 (26.1%)                 |                     |
| <i>Intensive Care excluding CPR and intubation</i>   | 7 (10.9%)                                       | 4 (7.3%)                                      | 11 (9.2%)                  |                     |
| <i>Medical Care</i>  | 8 (12.5%)                                       | 3 (5.5%)                                      | 11 (9.2%)                  |                     |
| <i>Comfort Care Only</i>   | 3 (4.7%)  | 0 (0.0%)                                      | 3 (2.5%)                   |                     |
| <i>Don't know</i>  | 1 (1.6%)  | 2 (3.6%)                                      | 3 (2.5%)                   |                     |
| <i>Didn't do</i>   | 1 (1.6%)  | 0 (0.0%)                                      | 1 (0.8%)                   |                     |
| <i>Missing</i>   | 1 (1.6%)  | 3 (5.5%)                                      | 4 (3.4%)                   |                     |
| <b>12. How things have changed for you since you got involved in this study</b>  |   |   |                            |                     |
| a) Values are expressions of what is most important to you as you consider the kinds of medical care you wish to receive when  |   |   |                            | 0.29                |

**Table 3. Telephone Follow up Assessment**

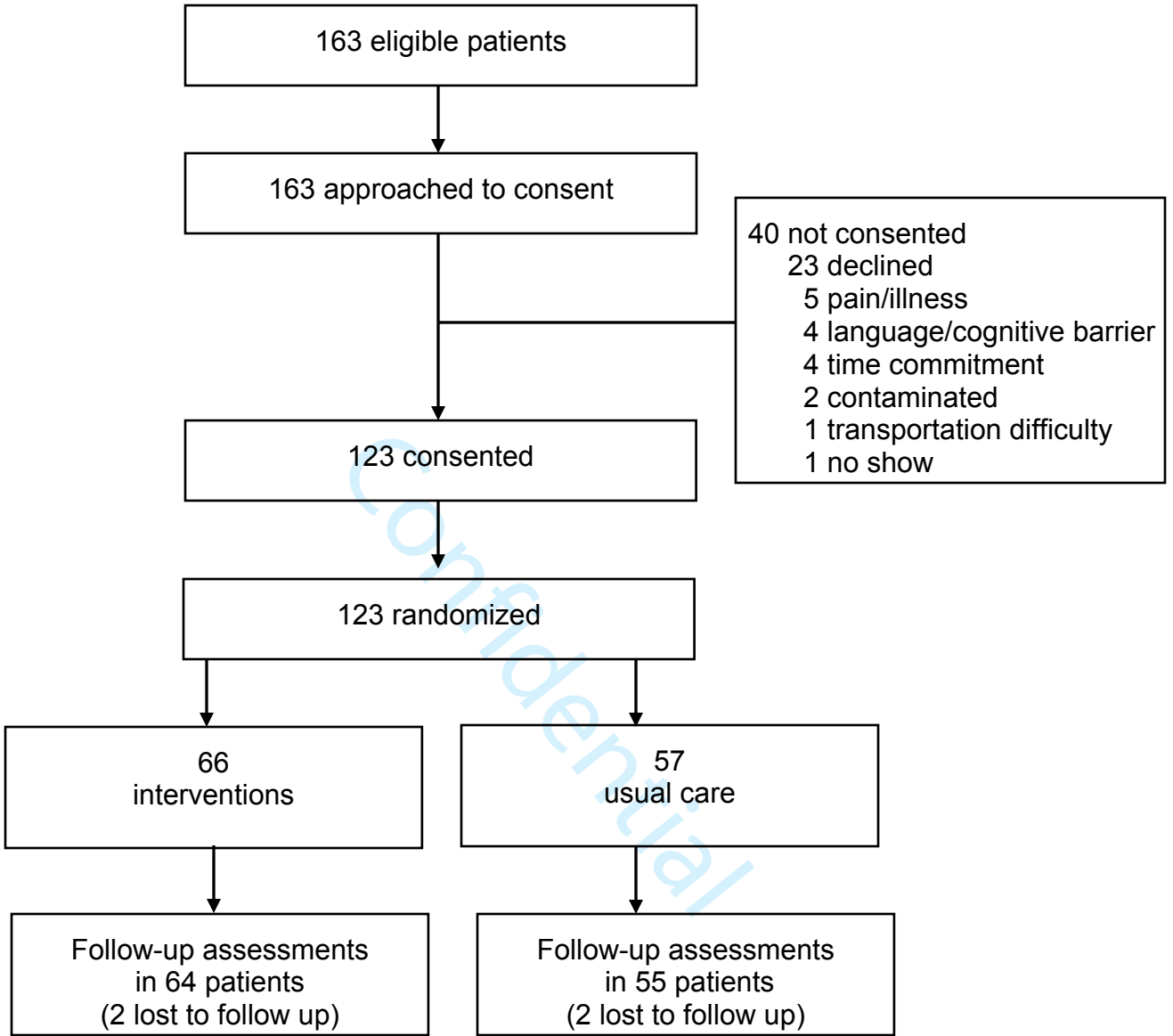
|  | <b>Intervention<br/>At follow-up<br/>(n=64)</b> | <b>Usual Care<br/>At follow-up<br/>(n=55)</b> | <b>Overall<br/>(n=119)</b> | <b>P<br/>values</b> |
|--|---|---|----------------------------|---------------------|
| seriously ill. Compared to before attending the clinic, are you more clear on your values or what matters the most to you?   |   |   |                            |                     |
| <i>No, no change</i>   | 13 (20.3%)                                      | 13 (23.6%)                                    | 26 (21.8%)                 |                     |
| <i>Yes, slightly more</i>  | 4 (6.3%)  | 5 (9.1%)                                      | 9 (7.6%)                   |                     |
| <i>Yes, somewhat more</i>  | 6 (9.4%)  | 5 (9.1%)                                      | 11 (9.2%)                  |                     |
| <i>Yes, moderately more</i>  | 11 (17.2%)                                      | 13 (23.6%)                                    | 24 (20.2%)                 |                     |
| <i>Yes, great deal more</i>  | 25 (39.1%)                                      | 16 (29.1%)                                    | 41 (34.5%)                 |                     |
| <i>Missing/ Declined</i>   | 5 (7.8%)  | 3 (5.5%)                                      | 8 (6.7%)                   |                     |
| b) Each of the treatment options presented on the last page has advantages, disadvantages and outcomes associated with it. Compared to what you knew before attending the clinic, do you know more about the various treatment options to make an informed decision? |   |   |                            | 0.02                |
| <i>No, no change</i>   | 5 (7.8%)  | 11 (20.0%)                                    | 16 (13.4%)                 |                     |
| <i>Yes, slightly more</i>  | 4 (6.3%)  | 4 (7.3%)                                      | 8 (6.7%)                   |                     |
| <i>Yes, somewhat more</i>  | 6 (9.4%)  | 8 (14.5%)                                     | 14 (11.8%)                 |                     |
| <i>Yes, moderately more</i>  | 17 (26.6%)                                      | 14 (25.5%)                                    | 31 (26.1%)                 |                     |
| <i>Yes, great deal more</i>  | 27 (42.2%)                                      | 15 (27.3%)                                    | 42 (35.3%)                 |                     |
| <i>Missing/ Declined</i>   | 5 (7.8%)  | 3 (5.5%)                                      | 8 (6.7%)                   |                     |
| c) Compared to before attending the clinic, do you have more support and advice from your family to make a choice?   |   |   |                            | 0.34                |
| <i>No, no change</i>   | 18 (28.1%)                                      | 17 (30.9%)                                    | 35 (29.4%)                 |                     |
| <i>Yes, slightly more</i>  | 3 (4.7%)  | 3 (5.5%)                                      | 6 (5.0%)                   |                     |
| <i>Yes, somewhat more</i>  | 7 (10.9%)                                       | 8 (14.5%)                                     | 15 (12.6%)                 |                     |
| <i>Yes, moderately more</i>  | 10 (15.6%)                                      | 10 (18.2%)                                    | 20 (16.8%)                 |                     |
| <i>Yes, great deal more</i>  | 21 (32.8%)                                      | 13 (23.6%)                                    | 34 (28.6%)                 |                     |
| <i>Missing/ Declined</i>   | 5 (7.8%)  | 4 (7.3%)                                      | 9 (7.6%)                   |                     |
| d) Compared to before attending the clinic, do you have more support and information from your doctor to make a choice?  |   |   |                            | 0.03                |
| <i>No, no change</i>   | 8 (12.5%)                                       | 11 (20.0%)                                    | 19 (16.0%)                 |                     |
| <i>Yes, slightly more</i>  | 1 (1.6%)  | 7 (12.7%)                                     | 8 (6.7%)                   |                     |
| <i>Yes, somewhat more</i>  | 10 (15.6%)                                      | 9 (16.4%)                                     | 19 (16.0%)                 |                     |
| <i>Yes, moderately more</i>  | 15 (23.4%)                                      | 9 (16.4%)                                     | 24 (20.2%)                 |                     |
| <i>Yes, great deal more</i>  | 25 (39.1%)                                      | 14 (25.5%)                                    | 39 (32.8%)                 |                     |

**Table 3. Telephone Follow up Assessment**

|   | <b>Intervention<br/>At follow-up<br/>(n=64)</b> | <b>Usual Care<br/>At follow-up<br/>(n=55)</b> | <b>Overall<br/>(n=119)</b> | <b>P<br/>values</b> |
|---|---|---|----------------------------|---------------------|
| <i>Missing/ Declined</i>  | 5 (7.8%)  | 5 (9.1%)                                      | 10 (8.4%)                  |                     |
| e) Compared to before attending the clinic, do you feel more SURE that your selected option is the best choice for you? |   |   |                            | 0.03                |
| <i>No, no change</i>  | 3 (4.7%)  | 7 (12.7%)                                     | 10 (8.4%)                  |                     |
| <i>Yes, slightly more</i>   | 2 (3.1%)  | 4 (7.3%)                                      | 6 (5.0%)                   |                     |
| <i>Yes, somewhat more</i>   | 5 (7.8%)  | 7 (12.7%)                                     | 12 (10.1%)                 |                     |
| <i>Yes, moderately more</i>   | 14 (21.9%)                                      | 11 (20.0%)                                    | 25 (21.0%)                 |                     |
| <i>Yes, great deal more</i>   | 35 (54.7%)                                      | 22 (40.0%)                                    | 57 (47.9%)                 |                     |
| <i>Missing/ Declined</i>  | 5 (7.8%)  | 4 (7.3%)                                      | 9 (7.6%)                   |                     |
| <b>13. Overall, how satisfied were you with the material presented to you by the GCD navigator or research nurse?</b>   |   |   |                            |                     |
| <i>3 - Slightly dissatisfied</i>  | 2 (3.1%)  |   |                            |                     |
| <i>4 - Neither satisfied not dissatisfied</i>   | 0 (0.0%)  |   |                            |                     |
| <i>5 - Slightly satisfied</i>   | 2 (3.1%)  |   |                            |                     |
| <i>6 - Moderately satisfied</i>   | 13 (20.3%)                                      |   |                            |                     |
| <i>7 - Very satisfied</i>   | 46 (71.9%)                                      |   |                            |                     |
| <i>Missing/Declined</i>   | 1 (1.6%)  |   |                            |                     |
| <b>14. How likely are you to recommend this program to others?</b>  |   |   |                            |                     |
| <i>2 - Probably would not recommend</i>   | 1 (1.6%)  |   |                            |                     |
| <i>3 - Might recommend</i>  | 3 (4.7 %)                                       |   |                            |                     |
| <i>4 - Probably would recommend</i>   | 14 (21.9%)                                      |   |                            |                     |
| <i>5 - Definitely would recommend</i>   | 41 (64.1%)                                      |   |                            |                     |
| <i>Missing/Declined</i>   | 5 (7.8 %)                                       |   |                            |                     |

**Table 4. What's Different About Plan Well Guide Compared to other ACP Tools?**

|    |   |
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| 1  |   |
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| 7  | Compared to other tools that may be used to help patients near or at the end of life, our   |
| 8  | Plan Well Guide offers the following features or attributes:  |
| 9  |   |
| 10 | <ul style="list-style-type: none"> <li>• Discriminates between planning for terminal care vs. planning for serious illness</li> </ul> |
| 11 | <ul style="list-style-type: none"> <li>• Explains how we make medical decisions under conditions of uncertainty</li> </ul>            |
| 12 | <ul style="list-style-type: none"> <li>• Utilizes a 'constrained' values clarification tool where respondents have to pick</li> </ul> |
| 13 | <ul style="list-style-type: none"> <li>• Utilizes a 'constrained' values clarification tool where respondents have to pick</li> </ul> |
| 14 | <ul style="list-style-type: none"> <li>• Utilizes a 'constrained' values clarification tool where respondents have to pick</li> </ul> |
| 15 | <ul style="list-style-type: none"> <li>• Utilizes a 'constrained' values clarification tool where respondents have to pick</li> </ul> |
| 16 | <ul style="list-style-type: none"> <li>• Uses 'Grids' to transparently connect states values to respondent preferences for</li> </ul> |
| 17 | <ul style="list-style-type: none"> <li>• Uses 'Grids' to transparently connect states values to respondent preferences for</li> </ul> |
| 18 | <ul style="list-style-type: none"> <li>• Uses 'Grids' to transparently connect states values to respondent preferences for</li> </ul> |
| 19 | <ul style="list-style-type: none"> <li>• Uses 'Grids' to transparently connect states values to respondent preferences for</li> </ul> |
| 20 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 21 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 22 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 23 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 24 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 25 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
| 26 | <ul style="list-style-type: none"> <li>• Provides a 'first in class' decision aid on the different levels of care, with</li> </ul>    |
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**Figure 1 – Patient Flow Diagram**

**eTable 1. Demographic Information on Participants in Development Phase**

|  |   |                      |
|--|---|----------------------|
|  |   | n=24                 |
| <b>Age</b>                                     |   | 78.3±10.5<br>(53-94) |
| <b>Sex</b>                                     |   |                      |
|  | Male  | 9 (37.5%)            |
| <b>Marital Status</b>                          |   |                      |
|  | Married or living as married  | 14 (58.3%)           |
|  | Widowed   | 8 (33.3%)            |
|  | Never Married   | 1 (4.2%)             |
|  | Divorced or separated; not remarried  | 1 (4.2%)             |
| <b>Where you been living in the past month</b> |   |                      |
|  | Own home  | 20 (83.3%)           |
|  | Retirement residence  | 4 (16.7%)            |
| <b>Highest level of education received</b>     |   |                      |
|  | University degree   | 2 (8.3%)             |
|  | Some university or completed community college; technical college or post-secondary program | 12 (50%)             |
|  | Completed secondary/high school   | 6 (25%)              |
|  | Did not complete secondary school or high school  | 4 (16.7%)            |
| <b>Language spoken daily</b>                   |   |                      |
|  | English   | 24 (100%)            |
| <b>Rated Quality of life</b>                   |   |                      |
|  | Excellent   | 1 (4.2%)             |
|  | Very Good   | 11 (45.8%)           |
|  | Good  | 10 (41.7%)           |
|  | Fair  | 2 (8.3%)             |
| <b>Comorbidities</b>                           |   |                      |
|  | Heart disease   | 14 (58.3%)           |
|  | High BP   | 17 (70.8%)           |
|  | Lung Disease  | 2 (8.3%)             |
|  | Diabetes  | 8 (33.3%)            |
|  | Ulcer or stomach disease  | 2 (8.3%)             |
|  | Kidney disease  | 6 (25%)              |
|  | Liver disease   | 0 (0%)               |
|  | Anemia or other blood disease   | 3 (12.5%)            |
|  | Cancer  | 2 (8.3%)             |
|  | Depression  | 4 (16.7%)            |
|  | Osteoarthritis, degenerative arthritis  | 10 (41.7%)           |
|  | Back pain   | 8 (33.3%)            |
|  | Rheumatoid Arthritis  | 1 (4.2%)             |
|  |   |                      |
| <b>Level of Fitness and Frailty</b>            |   |                      |
|  | Very Fit  | 2 (8.3%)             |
|  | Well  | 6 (25%)              |
|  | Managing Well   | 11 (45.8%)           |
|  | Vulnerable  | 4 (16.7)             |
|  | Mildly Frail  | 1 (4.2%)             |



**eTable 2. Results of Evaluation Phase (n=18 Lay Persons)**

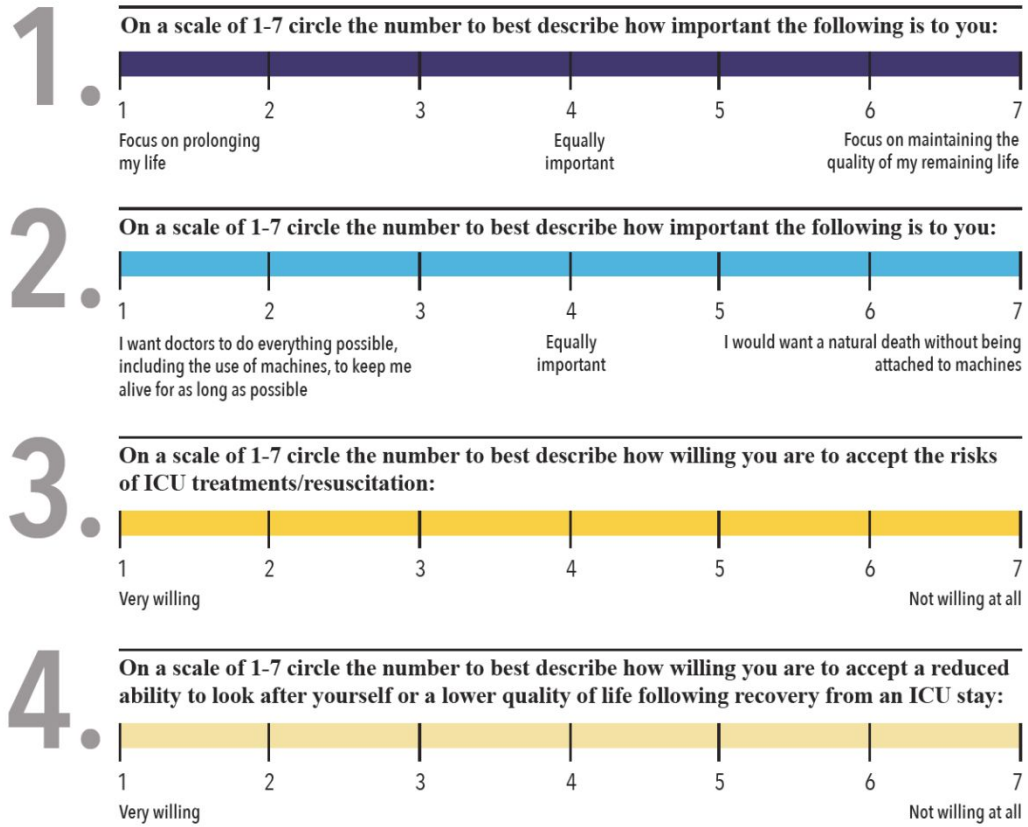
| Question   | Median | Range |
|--|--------|-------|
| How would you rate the language used in the tool?<br>(1 – Very Unclear, 5 – Very Clear)  | 4      | 1-5   |
| The amount of information in the tool was:<br>(1 – Much less, 3- about right, 5 – Much more)   | 3      | 2-3   |
| Overall, how difficult or easy was it to work through the tool?<br>(1 – Very difficult, 5 – Very easy)   | 4      | 3-5   |
| How helpful would this tool be for a patient who is thinking about<br>medical treatment for a serious illness?<br>(1 – Very Unhelpful, 5 – Very Helpful)   | 5      | 3-5   |
| How likely would you be to use this tool if your doctor<br>recommended it?<br>(1 – Definitely would not, 5 – Definitely would)   | 5      | 3-5   |
| How likely would you be to recommend this tool to someone else for<br>the purpose of discussing options for medical treatment of a serious<br>illness?<br>(1 – Definitely would not, 5 – Definitely would) | 5      | 3-5   |
| Overall, how would you rate the tool?<br>(1 – Very Poor, 5 – Very Good)  | 5      | 3-5   |

**eTable 3. Method for Eliciting Treatment Preferences in the Context of Serious Illness**

At this point in time, if life supports were needed to keep you alive, which option would you prefer for your care? Please choose (✓) one.

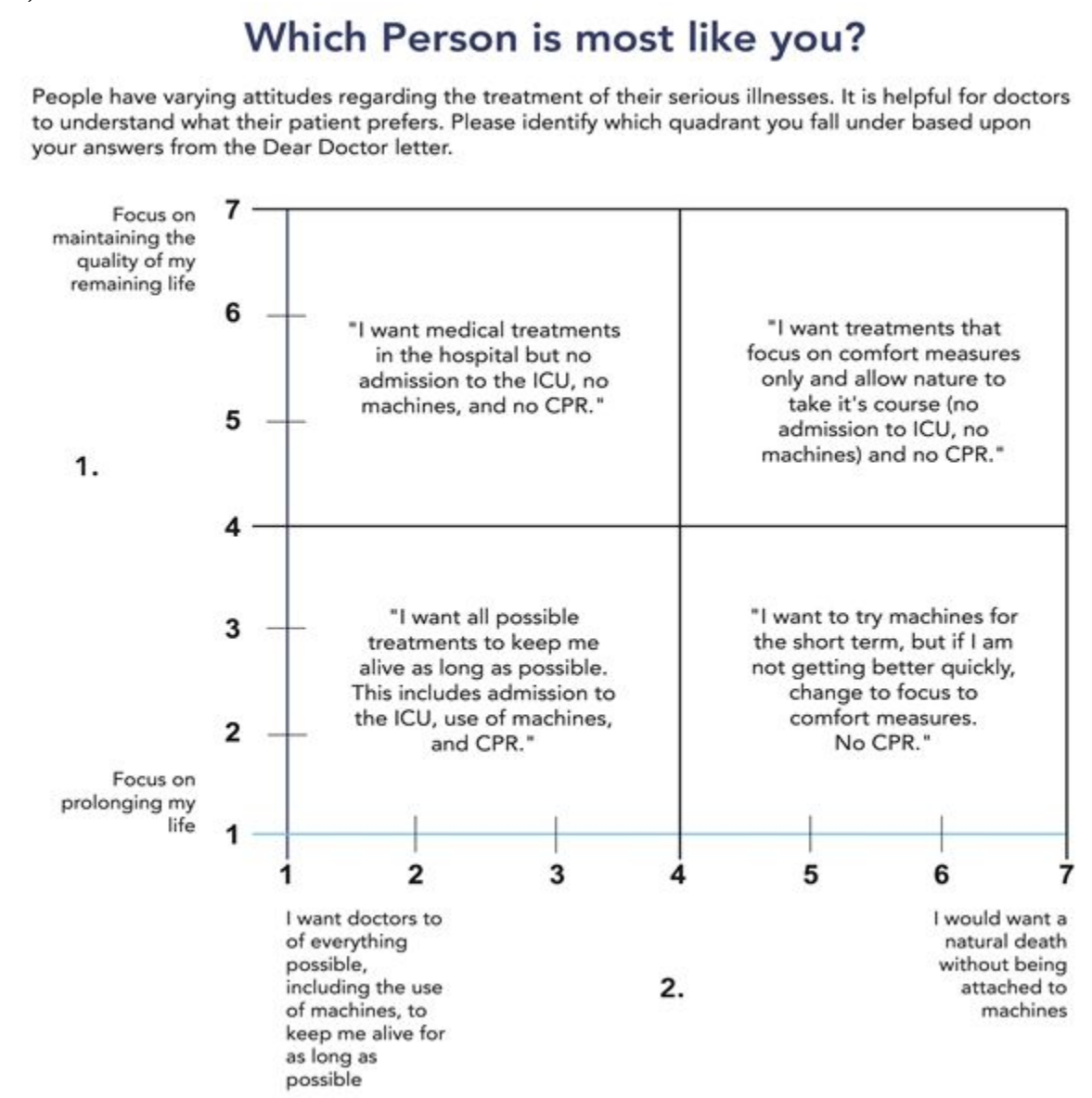
- 
1. Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
- 
2. Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation (CPR).
- 
3. Use machines only in the short term to see if I will get better but if the illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
- 
4. Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
- 
5. Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation (CPR).
- 
6. Unsure
-

eFigure1. Constrained Values Scales



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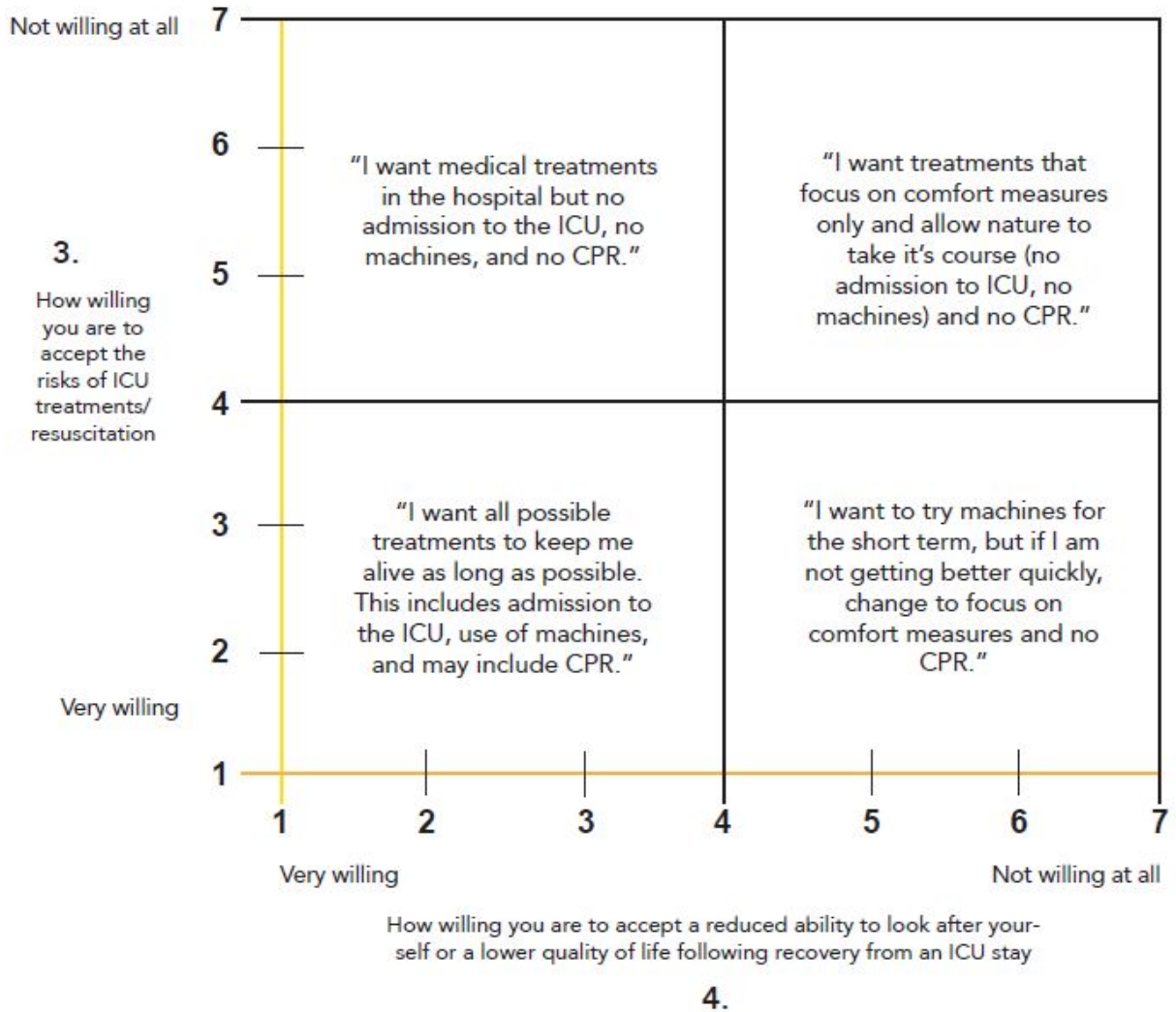
eFigure 2. Grid Indicating Relationship Between Values and Treatment Preferences  
A)



B)

## Which Person is most like you?

People have varying attitudes regarding the treatment of their serious illnesses. It is helpful for doctors to understand what their patient prefers. Please identify which quadrant you fall under based upon your answers from the Dear Doctor letter.





The facilitator provided education about the difference between ICU, Medical, and Comfort Care.

Showed me a 5 min CPR Video Decision Aid\* that describes the process of CPR, discusses treatment options and outcomes and helps clarify what is best for different patient groups.

Following review of these tools, we discussed the different treatment options available if I become I am seriously ill and I have indicated my preference below:

**At this point in time, if life supports were needed to keep me alive, I prefer:**

- 
1. Use machines and all possible measures including resuscitation (CPR) with a focus on keeping me alive at all costs.
- 
2. Use machines and all possible measures with a focus on keeping me alive but if my heart stops, no resuscitation (CPR).
- 
3. Use machines only in the short term to see if I will get better but if the illness is prolonged, change focus to comfort measures only. If my heart stops, no resuscitation (CPR).
- 
4. Use full medical care to prolong my life but if my heart or my breathing stops, no resuscitation (CPR) or breathing machines.
- 
5. Use comfort measures only with a focus on improving my quality of life and comfort. Allow natural death and no artificial prolongation of life and no resuscitation (CPR).
- 
6. Unsure

\* Please note the CPR video decision aid was not watched if patient was not interested in CPR (only if it was preferred or being considered)

**GCD Recommendation**

R1 R2 R3 M1 M2 C1 C2 C3

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**My nominated Substitute Decision-Maker(s) is/are:**

| Name: | Relationship with me: | Contact Information (optional): |
|-------|-----------------------|---------------------------------|
|       |                       |                                 |
|       |                       |                                 |
|       |                       |                                 |
|       |                       |                                 |

Finally, before we finalize the Goals of Care Designation form, I have the following questions, discussion points or other considerations regarding the values I've circled.

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Thank you Doctor for helping me plan and prepare for a very important time of my life.

Sincerely, \_\_\_\_\_  
(Patients name)