King’s Fund Digital Conference

Hearing the Patient’s Voice in an Emergency?
Survey Methodology

**Type of Survey** – Statistical review of 900 digitally created emergency, critical and advance care plans (advance decisions and statements)

**Sample Size** – 900 with representatives from all 50 US states

**Publication** – 1 July, 2016, Baylor University Medical Centre Proceedings

**Goal** – To explore whether the barriers to traditional advance care planning are reduced by using digital tools

**Objective** – To examine the results gained by a digital advance care planning tool through which consumers create, store, locate and retrieve advance directives

Study conducted by Robert L Fine, Office of Clinical Ethics and Palliative Care, Baylor Scott and White Health; Zhyong Yang; Christy Spivey; Bonnie Boardman and Maureen Courtney published in Baylor Proceedings
Why don’t people create Emergency, Critical, Advance Care Plans?

- Lack of awareness

- Falsely assume families know their wishes

- Equation with life-limiting treatments

- Believe they are complex to complete

- Believe they require lawyers and doctors to complete

BOTH UNTRUE

“70% of people will lack decision-making capacity at the time decisions near the end of life are needed.”
“Serious illness advance care planning conversations between physicians and patients lessen intensive treatment and lower expenditure, yet do not increase mortality.”
Preferences Described

94% want palliative Care

85% opted to stop life-sustaining treatment

70% want health agents involved in decisions

70% wanted CPR but not if doctor felt it would not work

76% opt to spend final days at home

62% wanted to be an organ donor

“30% of changes made more than 4 months after creation.”
What’s Important to You?

- 84% wanted to avoid dependence on machines
- 78% no tube feeding
- 85% wanted to be pain free
- 75% want to be with family in last days

“While most participants preferred cessation of life-sustaining treatment if terminally ill, 16% preferred a more nuanced approach.”
Survey Methodology

**Type of Survey** - Online survey conducted by NHS Choices. Self-selecting survey sample biased to digital users.

**Sample Size** – 15,637

**Survey Dates** – 19 November 2015 to 23 November 2015

**Goal** – To evidence the proposition that registered organ donors would be willing to create some form of appropriately accessible digital statement to reinforce their registration as an organ donor.

**Objective** – To provide NHS BT with enough evidence that a partnership with MyDirectives would bring direct benefits to NHSBT’s business and customers.
Age Distribution of Respondents

Takeaways

- More than 50% of respondents were between 25 and 44.
- More than 20% were aged 45 to 64.
- The survey also attracted 244 people aged 65 to 74 and 49 people over the age of 75.
- More than 86% of respondents were white.
How Confident Are You That Your Family Knows Your Views?

**Confidence in Family**

- Very: 52%
- Fairly: 31%
- Not Sure: 12%
- Not Very: 3.3%
- Not at All: 1.2%

**Takeaways**

- Confidence in the family knowing your views is still high at 52% but 43% are only fairly or not sure at all.
- By the time you get to extended family and friends confidence drops to a third being very confident, a third fairly and a third not sure.
Personal Message Creation

- Very Good Idea: 61.5%
- Good Idea: 30.1%
- Neutral: 6.3%
- Poor Idea: 1.5%
- Very Poor: 0.6%

**Takeaways**

- More than 10,000 people answered this question and more than 90% answered positively saying it was either a good or very good idea.

- This suggests significant support for further exploration of the concept.

- Total valid responses - 10,499
Likelihood of Creating a Personal Message

**Likelihood of Creation**

- **Definitely**: 43.7%
- **Probably**: 36.5%
- **Not Sure**: 12.4%
- **Probably Not**: 6%
- **Definitely Not**: 1.5%

**Takeaways**

- There is always a gap between acceptance of an idea and actual willingness to participate.
- Close to half - 43% - said they would definitely create a message with a further 36% positively saying they would probably create a message.
- From experience, the numbers of "probables" likely to convert will be determined by how easy the process is.
What Format Would You Be Most Likely to Choose?

<table>
<thead>
<tr>
<th>How to Record</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written Message on Website</td>
<td>57.9%</td>
</tr>
<tr>
<td>Video/Audio Message on Website</td>
<td>13.1%</td>
</tr>
<tr>
<td>Video/Audio Message on Phone</td>
<td>12.4%</td>
</tr>
<tr>
<td>Facebook Message</td>
<td>6.6%</td>
</tr>
<tr>
<td>I Would Not Create A Message</td>
<td>8%</td>
</tr>
</tbody>
</table>

**Takeaways**

- This confirms MyDirectives’ original proposition that people are willing to create structured messages on a website.
- Video picks up the largest vote after website with 12% but the concept is split between phone and website when technically there is no difference.
- Principal takeaway is that this group is very happy to engage with technology.
- There is no reason why the Facebook message couldn’t be a “selfie” video.
Would You Name Three People to Speak For You?

**Naming Agents**

- **Definitely Would**: 47.4%
- **Probably Would**: 31.2%
- **Not Sure**: 13%
- **Probably Not**: 6.2%
- **Definitely not**: 2.2%

**Takeaways**

- Almost half in favour of “naming agents” with another 31% saying they probably would.
- Suggests organ donors are very willing to help ensure their wishes are fulfilled.
MyDirectives’ Apple iPhone Collaboration