



A|D Vault™

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July 2016

•  
King's Fund Digital Conference  
Hearing the Patient's Voice in an Emergency?

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## Survey Methodology

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**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?

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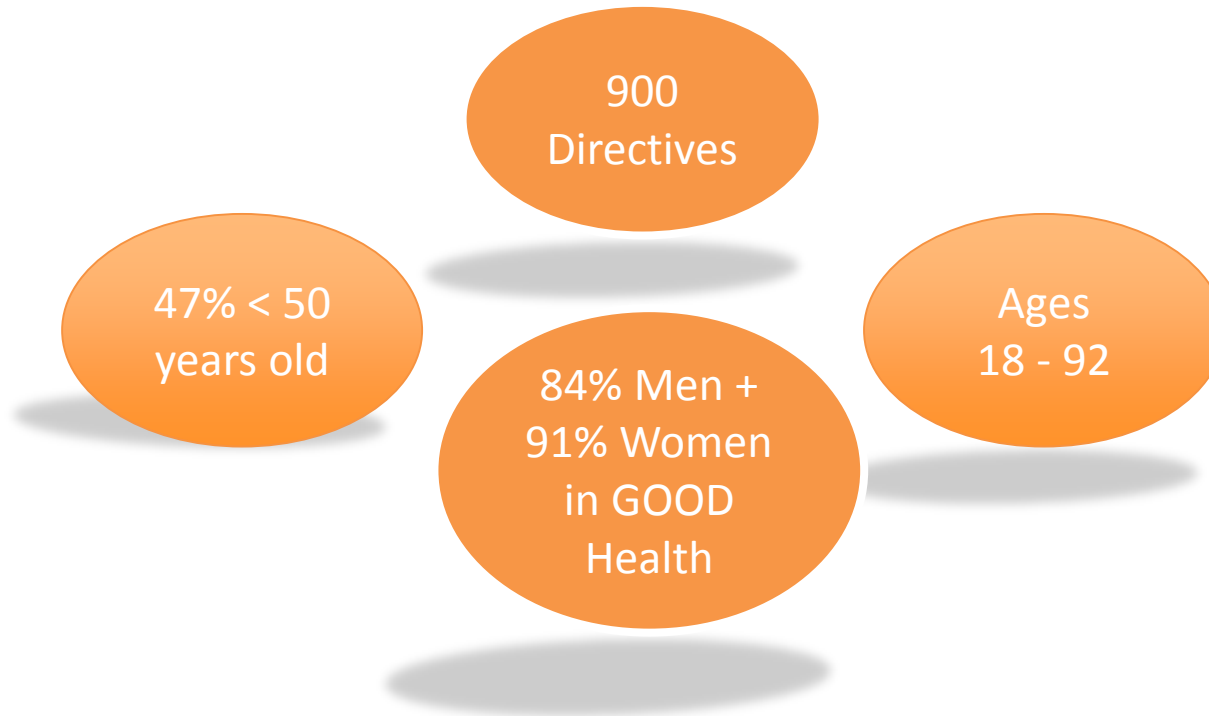
- Lack of awareness
- Falsely assume families know their wishes
  - Equation with life-limiting treatments
  - Believe they are complex to complete
- Believe they require lawyers and doctors to complete

“70% of people will lack decision-making capacity at the time decisions near the end of life are needed.”

**BOTH UNTRUE**



## Baylor Scott and White Sample



“Serious illness advance care planning conversations between physicians and patients lessen intensive treatment and lower expenditure, yet do not increase mortality.”

ALL AGES/MAJORITY IN GOOD HEALTH



## Preferences Described

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70% want  
health agents  
involved in  
decisions

94% want  
palliative  
Care

85% opted to  
stop life-  
sustaining  
treatment

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

62% wanted  
to be an organ  
donor

76% opt to  
spend final  
days at home

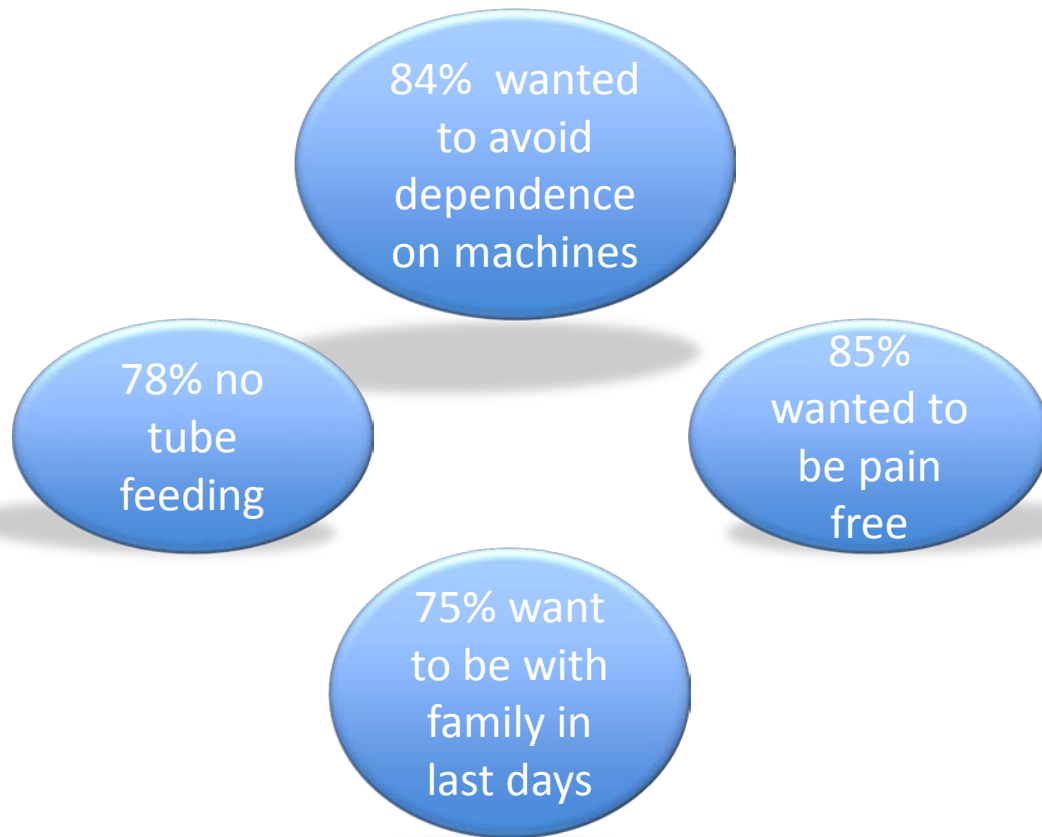
“30% of changes made  
more than 4 months  
after creation.”



## What's Important to You?

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



## Survey Methodology

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**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

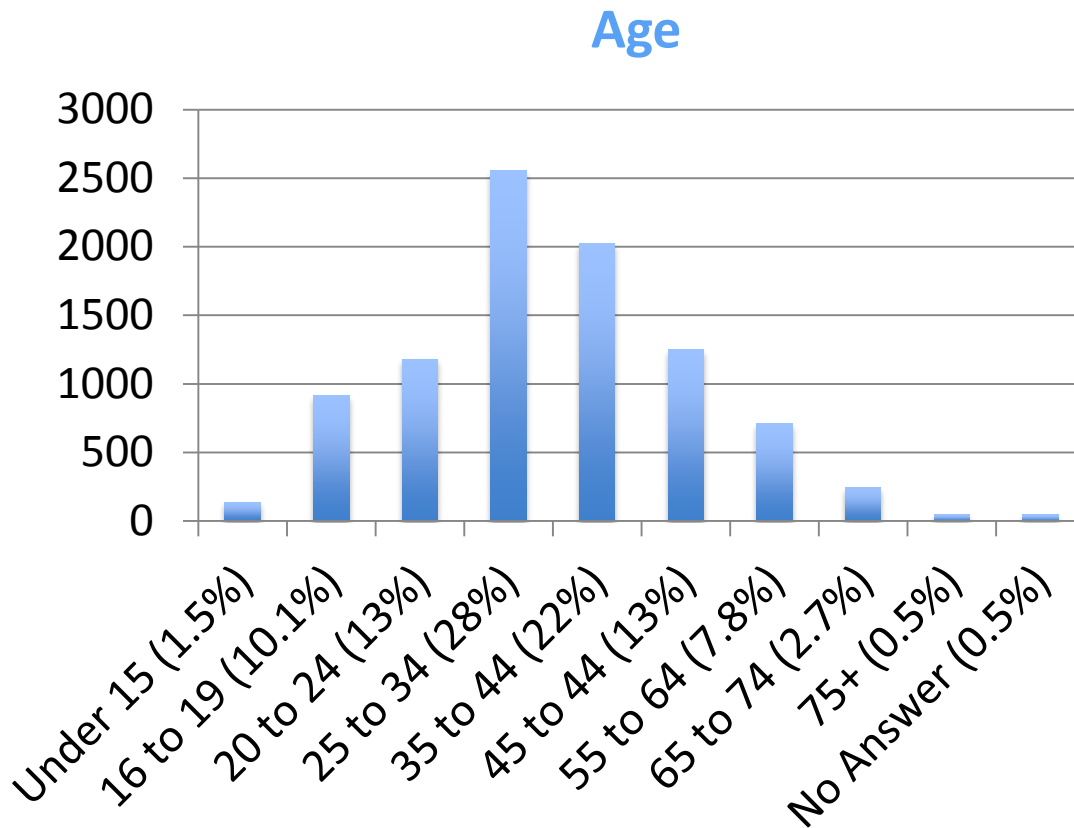
**Objective** – To provide NHS BT with enough evidence that a partnership with MyDirectives would bring direct benefits to NHSBT's business and customers

Survey conducted on  
NHS Choices between  
Thursday 19<sup>th</sup>  
November and Monday  
23<sup>rd</sup> November 2015



## Age Distribution of Respondents

### Takeaways



■ Age

- 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.

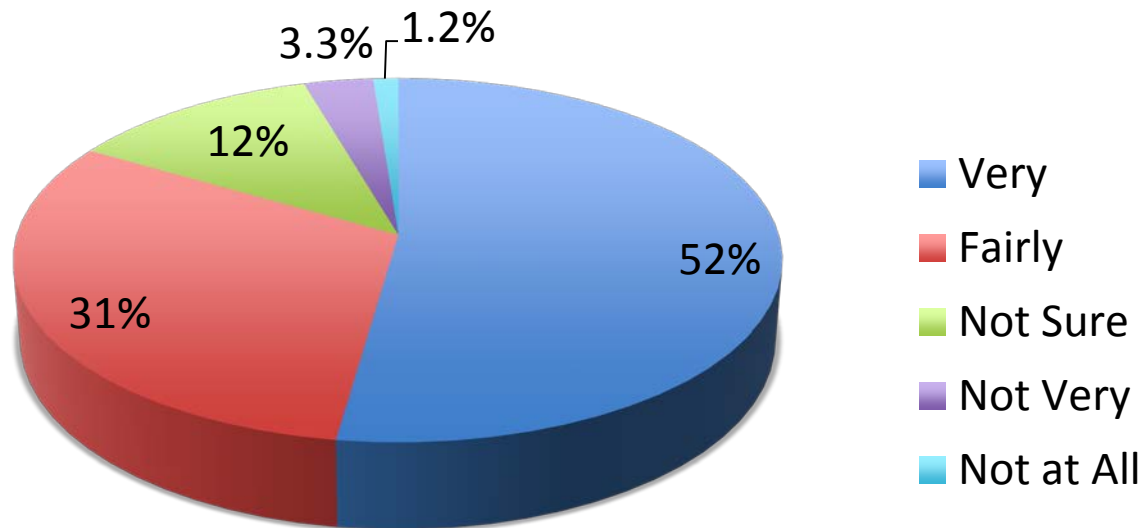




## How Confident Are You That Your Family Knows Your Views?

### Takeaways

### Confidence in Family

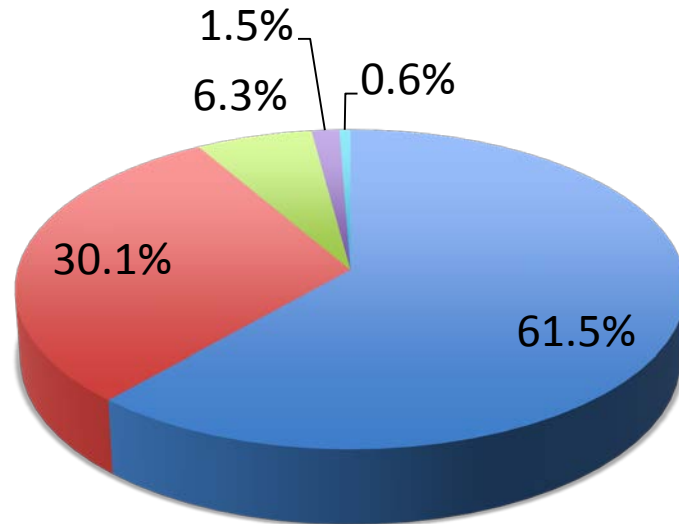


- Confidence in the family knowing your views is still high at 52% but 43% are only fairly or not sure at all.
- By the time you get to extended family and friends confidence drops to a third being very confident, a third fairly and a third not sure.



## Creating a Personal Message

### Personal Message Creation



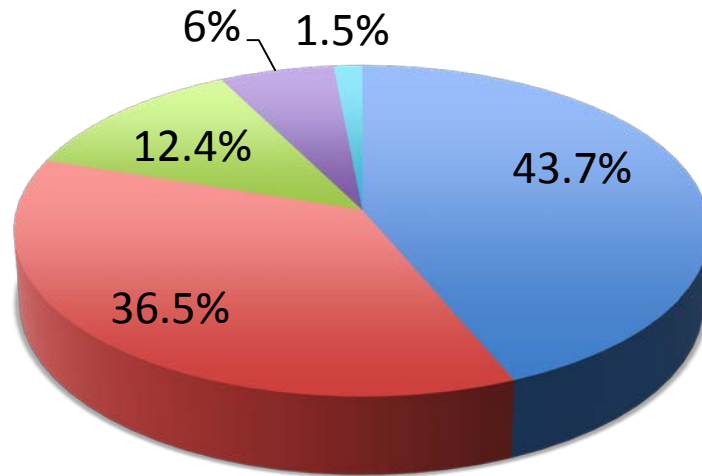
- Very Good Idea
- Good Idea
- Neutral
- Poor idea
- Very Poor

#### 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
- Probably
- Not Sure
- Probably Not
- Definitely Not

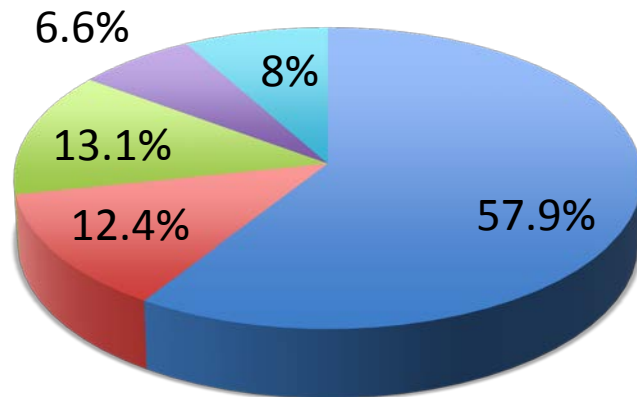
#### Takeaways

- 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?

### How to Record



- Written Message on Website
- Video/Audio Message on Website
- Video/Audio Message on Phone
- Facebook Message
- I Would Not Create A Message

### Takeaways

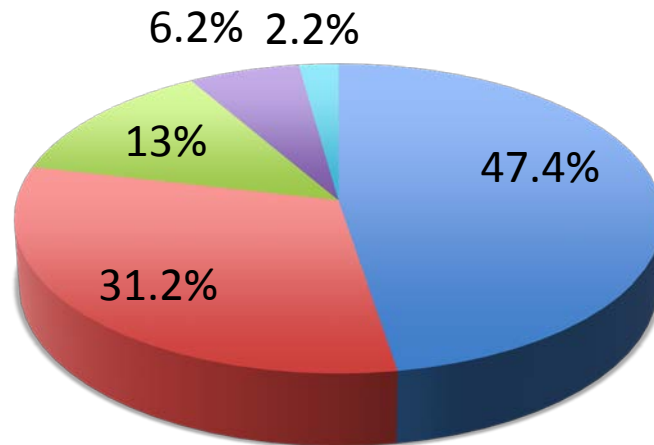
- This confirms MyDirectives' original proposition that people are willing to create structured messages on a website.
- Video picks up the largest vote after website with 12% but the concept is split between phone and website when technically there is no difference.
- Principal takeaway is that this 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?

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### Naming Agents



- Definitely Would
- Probably Would
- Not Sure
- Probably Not
- Definitely not

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#### 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.
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## MyDirectives' Apple iPhone Collaboration

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