

2018 Innovating for Ageing Programme

Problem Shortlist

End of Life Planning

Anthemis – End of life planning and consumer vulnerability

What is the issue facing vulnerable consumers that you would like us to ask the solutions community to attempt to solve?

"Time and again, hospice professionals see families in the hallway of the emergency room or ICU trying to figure out what Mom or Dad might have wanted, and that's a very tough time to think these things through. People often put more thought into preparing for the family vacation—the transportation, the timing, the meals—than planning for the end-of-life experience we'll all have." Concept/Issue: As people age, the importance of end-of-life planning increases dramatically.

However, many tend to neglect end-of-life planning; compromising the health, emotional and financial affairs of the individual and their family. This creates complications across the spectrum. To ensure their best interests (and those of their family) are accounted for, there is an opportunity to change this. Note: This problem is faced by consumers in the UK and US markets. I have additional evidence of the problem in the US context, but for the purposes of the project, I have limited my explanation to the UK market only.

The origins of inspiration/passion for solving this issue is a by-product of Atul Gawande's book titled 'Being Mortal', specifically Chapter 6 titled 'Letting Go'. Whilst Gawande contextualises the problem with respect to the US market, it has direct parallels with the UK market. He describes 'ars moriendi' (the art of dying), relating to Latin texts dating from the 1400's which prescribed customs that people followed when they died. However, advancements in medical care have lengthened the death process which creates a new difficulty for mankind – How to die. Simply put, "if end-of-life discussions were an experimental drug, the FDA would approve it".

He states that seriously ill patient's typically desire to: - Avoid suffering - Strengthen relationships (with family and friends) - Be mentally aware - Not be a burden on others - Achieve a sense that their life is complete Evidence provided indicates that in most cases, these desires are not met. However, with effective end-of-life planning, the patient's medical wishes can be met whilst ensuring that their family and friends are not burdened by tensions with doctors, nor financial complications arising from the inevitable death of a loved one.

The root cause of the problem is largely attributable to various factors at play. While I go into greater detail in question two, these factors (not limited to) traditionally prevent consumers from actively seeking and partaking in end-of-life planning: - 'Attitudinal and emotional barriers' - ignorance problem (choose to ignore and/or procrastinate) - 'Relevance barriers' - misunderstanding problem (relating to the law) - 'Practical barriers' - nomination problem (nominating family and friends) - Information barriers' - awareness problem (different options available) - 'Process barriers' - cost problem (perceived to be too expensive) This is where

innovation in the end-of-life planning space can create an impactful difference.

While many understand the importance of planning for the inevitable, little action is taken. Death is a sensitive topic and many choose to avoid it. This is likely related to superstitions such as 'tempting fate', whereby many hide behind 'health status' and 'death anxiety' to avoid discussing death.

Inevitably, I believe that if we can create greater access to end-of-life planning services, and educate the market; then we can create a fundamental shift in market sentiment and mitigate consumer vulnerability.

Why should the judges ask the solutions community to prioritise the issue you have proposed?

Primary Benefit (Meeting the Patient's wishes) 75.5% (460 000) of 600 000 UK deaths (2015) have a 'predictable death' (i.e. poor health), and 1 in 5 of these predictable deaths have an unmet need for expert end-of-life care (averages £4 500+ during the last three months of a person's life). Furthermore, 1 in 5 of patient's care decisions were not aligned with their wishes. The law states that people must be assumed to have capacity unless proven otherwise. Without effective end-of-life planning, the default is that only the healthcare professional has the final say on a patient's treatment (not family or friends).

The healthcare professional also can't share any information about the patient's care or treatment with the family. Yet, most are unaware of this. The current set of end-of-life planning documentation is as follows:

1. Lasting Power of Attorney (LPA): Personal welfare (medical) VS property & financial affairs
2. Living Will/Advance Directive/Advance Decision to Refuse Treatment: Medical wishes
3. Advanced Statements (forms part of an Advance Care Plan): Wishes, beliefs and values
4. Advance Care Planning: Care preferences (location, people and treatment decisions)
5. DNAR/DNACPR Forms/Order and CPR Decisions: Refuse CPR only
6. Last Will and Testament: Distribution of property & possessions after death.

While 70% of the British public say they are comfortable talking about death (2015), 36% of the British public don't know where to find information to consider effective end-of-life planning. These inferences can be applied to the UK market, as research indicates that <1% of the UK population has an LPA (30% health; 70% financial), only 5% have a Living Will/Advance Directive/Advance Decision to Refuse Treatment (ADRT) and 11% have written funeral plans. While the Last Will and Testament is the most common form of end-of-life planning known to the general public, ~60% of UK citizens don't have one and 50% have not updated theirs.

The biggest roadblock to innovation is the current construct of the UK legal system. This being because all legal documents must be signed by a testator in the presence of two witnesses. Many have tried digitising specific documentation outlined above, however the witnessing

component prevents the opportunity for a fully-digital solution. It is clear that the UK law, based on 19th century laws, requires modernisation. While the Law Commission has published a consultation paper on this (specifically relating to Last Will and Testaments) the results will only be made available in Q3/Q4 of 2018. To be clear, currently no major legal jurisdictions in the world provides for electronic legal documentation with respect to the above. Whilst it was proposed in the United States, there has been no successful implementation (Nevada introduced a statute in 2001, but the technological requirements were too stringent for majority to comply with).

Secondary Benefit (Cost saving for families and hospitals) The NHS wastes ~£2.3bn per annum on unnecessary or expensive treatments. By ensuring that a patient has taken pro-active steps to plan for their end-of-life, this has second-order financial benefits. End-of-life planning ensures the patient's medical preferences/wishes are met, which inevitably can reduce the initial assumptions to undertake expensive medical treatments for the sake of longevity. Resultantly, this prevents both the family and the NHS (or hospital provider) from taking-on the associated financial burden.

How many people might benefit from a solution to this issue?

Another client did not do any of his estate planning until after he was diagnosed with a terminal illness. Because of his terminal illness, both his physical health and mental health were impaired. On top of that, the medication he took to control his pain further impaired his mental faculties. In order to ensure that my client's estate plan would be enforceable, I had to question him over a period of days to prove that he was mentally competent. This rigorous deathbed estate planning made my client anxious and aggravated. It pained me to steal precious time from his dying days to do estate planning that could have done at a leisurely pace much earlier in his life."

Baby Boomers. The nature of the problem appeals to all generations of society (the UK population sits at 65.6 million, its largest ever). There are 18.9 million families in the UK that will directly benefit from effective end-of-life planning. However, I feel that the core focus should be placed on the Baby Boomer generation (born roughly between 1945 and 1965). Baby Boomers, own more than half of Britain's £11 trillion of wealth, which is alarming because most do not have end-of-life contingency plans (see question 2). While there are no public statistics indicating the exact amount of Baby Boomers in the UK currently, 11.8 million members (18%) of the UK population are aged 65 and over.

While 75.5% (460 000) of 600 000 UK deaths (2015) have a 'predictable death' (i.e. poor health), approximately 50% of these deaths are apportioned to 65 - 85 year olds (including external causes). Accounting for the predictability, wealth and other generational factors; Baby Boomers are a key segment to benefit from a possible solution. Note: Changing social demographics have made it increasingly difficult to identify the 'dying-phase'. This is a result of the interrelatedness of an ageing population, funding and workforce pressures. As such, I believe this issue is of critical importance to all consumers as they are all essentially 'vulnerable'.

If you have any case studies to exemplify the problem, please provide details here

Note: The exemplary case studies below apply specifically to the US market. There is a clear market opportunity to address this issue in the UK, and based on my research there is no credible solution within the UK currently.

1. Respecting Choices ACP (La Crosse, Wisconsin) "It turns out that if you allow patients to choose and direct their care, then often they choose a course that is much less expensive." Model Value proposition:

Ensuring patient's wishes are met, while providing a potential cost saving to their families and hospitals → Script for having conversations about the end of life (3 or 4 consultations to complete) → Collaboration between Bud Hammes, Gundersen Health & other health providers → Practical training on how to have difficult conversations with patients and families → 10 000 trained facilitators across 130+ health systems and medical centres globally → 1995: 85% take-up ; 2009: 96% (3x+ national average) Problem (Revenue Opportunities) → Hospitals do not earn money from the Respecting Choices ACP (sustainability concerns) → The ACA encourages providers to reduce spending, which could see greater implementation → Average cost of patient's last two-years was \$18 159 in La Crosse VS \$26 000 national average

2. Vital Decisions (acquired by MTS Health Investors in 2012) "An Advance Directive alone is not enough – this is about improving the communication and shared decision making among clinicians and family members, and recognizing the importance of changing the behaviours of the participants in the process." Model Value proposition: Save providers (and insurers) money, while ensuring the patient's wishes are met → Specialists in Advance Care Planning (ACP) behavioural science → Partnerships with 20+ health plans to identify those most in-need (not limited to government) → Gains access to 'Medicare Advantage' claims data for terminally ill patients → 200+ employees (masters-level education with 3+ years of industry experience) → 2.7M lives covered (30K+ new individuals each year) @96% customer satisfaction → Saves ~\$250M for providers (6:1 ROI for intervention members) → ~\$14K savings during patient's last six-months of life (23% - 26% lower end-of-life costs)

Legal and General Home Finance – Complexity of LPAs

What is the issue facing vulnerable consumers that you would like us to ask the solutions community to attempt to solve?

The UK population is on average getting older and this change in demographic requires customers to think and plan for their future. It is evident that not all older consumers are vulnerable, however they are more likely to experience momentary or permanent vulnerability than younger demographics, due to health, resilience, capability and life events. Customers should be encouraged to manage their financial affairs themselves for as long as they can.

However, as customers experience cognitive decline or certain life events, they may struggle to manage independently and need support from someone they trust, like a relative or friend with caring responsibilities. Problems with engagement and confusion of third party access, often result in a significant number of older customers resorting to workarounds to manage financial transactions and these 'coping mechanisms' may not meet the needs of the older person and their carer. The FCA recently launched their 'Ageing Population' paper which focused on the risks of older customers' financial services needs not being fully met, resulting in exclusion, poor customer outcomes and potential harm.

Third party access played a critical role in this paper and was deemed extremely important for consumers who can't manage their money by themselves. The FCA highlighted the need for Government, industry and consumer groups to have a key role in ensuring that people are aware of third party access options and opt for one that will fully meet their needs through improved systems, processes and communications. Although, it is important that firms across financial services offer their customers a range of third party access options, the certainty and safeguarding around Lasting Powers of Attorney needs to be leveraged.

A Lasting Power of Attorney is a legal document where one person, the 'do-nor', authorises one or more people, the 'attorney(s)', to make or help make decisions for the donor. It can sometimes be difficult for customers to think about a time when they won't be able to make their own decisions. However, it is extremely important to plan and have the peace of mind that someone they trust will be able to make decisions on their behalf when the time comes.

If a Lasting Power of Attorney is not in place and there comes a time when a customer loses mental capacity to make their own decisions, and individual would have to apply for authority from the courts to manage their affairs. This is a lengthy and expensive process which can take up to 6 months; it also means the customer won't have a say in who manages their affairs. This poses a risk to not only the customer but also the financial services provider, the firm would not be able to speak to anyone or action anything on the account until someone has obtained a court order on behalf of the customer.

Legal & General Home Finance have identified challenges faced when encouraging customers to consider and set up a Lasting Power of Attorney, which include:

1. A lack of awareness of LPA and why customers should protect themselves for future events.
2. There seems to be a stigma attached to LPA and it is a sensitive subject for many, customers do not want to admit defeat or give in to help especially when it is before the event.

3. There is a significant cost associated to registering a LPA, especially if customer does not have the confidence to apply themselves and requires legal advice which could cost in the region of £750-900.
4. The form filling and organisation of the registration can be a laborious and confusing task for many which encourages people to leave until it's too late. There-fore, we would like you to ask the solutions committee to attempt to remove the complexity and cost (where possible) of placing an LPA in place.

Why should the judges ask the solutions community to prioritise the issue you have proposed?

1. ONS statistics show Dementia and Alzheimer's disease as one of the most common causes of death in the UK.
2. LPA allows people to delegate authority for financial and/or welfare matters to someone they trust.
3. Setting up an LPA ensures that a person's wishes relating to who should make the decisions are respected, this prevents a stranger from having the power.
4. An LPA makes easier for family and friends and is less expensive, easier route than applying for a court order.
5. Having an LPA in place avoids the difficult time consuming and costly court and monitoring process that appointing a deputy requires.
6. An LPA could save thousands of pounds in annual fees to the Office of the Public Guardian (OPG), fees are payable by deputies for supervision by the OPG.
7. Financial Services product providers face barriers in relation to servicing products when there has been a loss of mental capacity without an LPA in place.
8. Once you have the LPA document, the customer can register with financial services firms who will then treat the attorney as if they were the original customer, allowing them to act on the customers behalf.
9. Even when a customer chooses to register the LPA, they are still able to manage your own affairs until you are no longer able to do so.

How many people might benefit from a solution to this issue?

ONS figures show the mean population is getting older, in 2016 in the UK, 18% of people were aged 65 and over and 2.4% were aged 85 and over. Because of the ageing population the old age dependency ratio (QADR) is increasing. The QADR is the number of people over 65 years old for every 1,000 people ages between 16-64 years old – in mid-2016 the UK's QADR was 285. In 2017, the FCA stated while one in six of the UK population is currently aged 65 and over, by 2050 one in four will be. Over 2.6 million people have Lasting Powers of Attorney (LPA) registered with the Office of the Public Guardian (OPG) in England and Wales. In 2016/17, 648,318 LPAs were registered, an increase of 18% on the previous year.

Compassion in Dying – Awareness around LPA and Advance Decisions

What is the issue facing vulnerable consumers that you would like us to ask the solutions community to attempt to solve?

Compassion in Dying helps people prepare for the end of life: how to talk about it, plan for it, and record their wishes.

We do this through our free information line, publications and resources, and through our work with diverse communities. We specialise in supporting people to make Advance Decisions ('Living Wills') and to talk about their goals and priorities when living with a life-changing illness. Our free MyDecisions website helps people to record their wishes for care in a legally binding way.

We supported over 5,700 people in 2017 and have already received more than 2,000 calls in 2018. In 2017, we trained 146 healthcare providers including care home staff and reached a further 970 health and care professionals involved in Clinical Commissioning Groups, hospices and dementia care for example, through conference presentations and workshops. We have also worked across England and with older South Asian, Somali and LGBT* people and have a good understanding of how health inequalities arising from different socio-cultural and economic contexts impact on end of life decision-making in practice.

These experiences inform our application to you.

Issues

1. Despite national efforts to improve access to end-of-life care information and services, many people do not know about their rights to plan ahead as set out in the Mental Capacity Act 2005 (MCA). For example:

- a. There is limited awareness around the tools available for planning ahead (Lasting Powers of Attorney, Advance Decisions to Refuse Treatment and Advance Statements).
- b. There is a misconception that it is mandatory to involve solicitors and healthcare professionals in planning ahead.
- c. Many hold the mistaken belief that preparing these documents costs money when in fact Advance Decisions and Advance Statements are available for free and Lasting Power of Attorney (LPA) costs £82 to register, with discounts available to some.
- d. Many people mistakenly believe that their family can make the final decisions about their treatment and care, if they do not have capacity to make the decisions themselves.

2. Not all health and care professionals are aware of their responsibilities under the Mental Capacity Act and so are not confident about supporting people to plan ahead; respecting treatment preferences and making best interests decisions. We have observed this during the training sessions we have conducted with health and care professionals and have also received numerous reports from callers who have struggled to get support from their service providers. While we regularly engage with disease/condition-specific charities, government departments and NICE to address this challenge, much more needs to be done if the commitment to person centered care is to be realised.

3. Finally, we have been documenting numerous instances of solicitors and organisations disseminating incorrect information about Lasting Powers of Attorney and Advance Decisions. Providing information that is factually incorrect and incompatible with the Mental Capacity Act and charging a fee for a "service" that is available for free, which is particularly concerning when it directly impacts people's ability to plan ahead and their decision-making for the end of life.

Why should the judges ask the solutions community to prioritise the issue you have proposed?

- Being involved in decisions about and having access to treatment and care that aligns with one's values and beliefs is a human right. Enabling the realisation of this right through existing legislation (the Mental Capacity Act 2005) is vital if end-of-life care is to be person-centered.
- A 2014 YouGov survey found that 82% of people they have strong wishes about how they would like to be treated at the end of life but only 4% have set out their wishes in a legally binding way. In light of the lack of information and numerous instances of misinformation, this is sadly not surprising.
- With an ageing population and increasing numbers of people affected by dementia, supporting people to plan ahead so that they receive the care and treatment that is right for them becomes particularly important.
- In 2016, we commissioned the International Longevity Centre to undertake a literature review of the impact of advance care planning which found that the process of thinking about and recording one's treatment and care preferences results in better person-centred care and improved relationships and communication between patients, families and healthcare professionals. It is vital therefore that people are given opportunities and support to plan ahead for future care and treatment.
- Through our services we have also learnt that when people are supported to plan ahead, they are more likely to receive treatment and care that is in line with their values and beliefs, and that they are also given peace of mind - enabling them to live well in the present with the reassurance that people will know their wishes when they can't speak for themselves. So planning ahead, for example by making an Advance Decision improves quality of care received in the future, and quality of life at the time it is made.
- Importantly, for some people, the process of thinking about, discussing and recording their wishes is not easy. Healthcare professionals are often reluctant to talk about death and dying, can struggle to start the conversation and often do not have the time to support individuals through the process of planning ahead. This can leave many people feeling disempowered and vulnerable.
- This is further exacerbated among communities who face health inequalities, such as BAME communities and LGBT* individuals.

During our work with Opening Doors London, we heard many examples where LGBT* people had significant others (for example their partner or a close friend) who they wanted to make decisions. However, in the absence of a Lasting Power of Attorney or Advance Decision setting out wishes for treatment, when the individual lost capacity, their family members, who often

hadn't been in the person's life for several decades, were consulted. Many felt that as a result an aspect of that person's identity was lost and that the person received care that was not aligned to their wishes and values in the way it would have been if those genuinely close to them had been involved in decision-making.

How many people might benefit from a solution?

Planning ahead is important for any adult who has strong feelings about the treatment and care they would, or would not, want to receive if they were unable to make decisions for themselves.

But while this issue is important for all adults, tackling the issues raised above may particularly benefit older people, and people with a life-changing diagnosis. 82% of those who contact our information service are aged 65 and over. Our experience of delivering face-to-face support to people to plan ahead through our My Life, My Decision project was that 20% of those who used the service had a diagnosis of dementia. These people felt a pressing need to plan ahead for future care whilst they still had the capacity to do so.

Tackling the issues we have raised may also have a particularly positive impact on people who are unable or less confident to question misinformation. Further to this, ensuring that rights and responsibilities in relation to end-of-life care are well understood would greatly benefit carers and health care professionals.

We also know from our services that many health and care professionals would like more people to be engaged with their own health, and to record their preference for treatment and care, so that they aren't left guessing about patients' preferences.

Similarly, many carers have told us that the fact their family member had either made an Advance Decision or a Lasting Power of Attorney made them as a carer much more confident in conveying their loved one's views to healthcare professionals, and relieved that they were able to ensure their loved one's wishes were respected.

This learning from our services is supported by the findings of a literature review on advance care planning that we commissioned in 2016, which found that the process of thinking about and recording treatment and care preferences facilitated and resulted in improved relationships and communication between patients, families and healthcare professionals.

If you have any case studies to exemplify the problem, please provide details here

1) A common statement from callers is "I didn't know I could do this and that I could do it for free!"

2) We regularly hear of negative experiences when discussing Advance Decision with GPs and of being charged between £50- £100 for the appointment.

"The GP thought that my Advance Decision meant I did not want any further treatment as of now! I explained that it was a refusal of treatment for when I lost capacity to make decisions myself. The administration department refused to record my Advance Decision on my medical notes and destroyed the copy I had given them." (April 2018)

“When I spoke with my GP about making an Advance Decision, they said I needed a capacity assessment done by a psychiatrist and a solicitor and didn’t explain why.” (March 2018)

These examples highlight the lack of awareness among healthcare professionals about peoples' rights to plan ahead; about their responsibilities as healthcare professionals under the MCA and the lack of engagement with the principles of shared decision making.

3) People are often given incorrect information about their rights by solicitors. While we understand that solicitors are free to charge, this is a significant barrier to people wishing to plan ahead. Our callers have been quoted up to £1500 by solicitors to complete and register LPA forms when in fact registration costs £82 and support to complete it is available for free.

Examples of misinformation and poor practice:

- Advance Decisions are only for people with a terminal illness
- There is no such thing as an Advance Decision
- An Advance Decision is not legally binding
- You cannot have an Advance Decisions and an LPA for health and welfare

“I bought an Advance Decision pack from a company via Amazon. The pack never arrived and it took ages to get a refund. I was really put off making an Advance Decision, even though I have very strong views about how I want to be cared for. Your service was recommended on a TV programme and I feel confident to start the process again.” (April 2018)