The lived experience of older adults
Key messages
A report prepared for the Technology Strategy Board

Experience Research and Consulting Limited
People centred research & innovation
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1. Overview

1.1 About the Report

‘The Lived Experience’ is a report on research commissioned by the Technology Strategy Board (TSB) as part of its Revolutionising Long Term Care initiative. This initiative seeks to radically rethink current models of long-term care and dependency to create new and desirable alternatives leading to structural and economic change for the future. The intention is not to reform or remodel what already exists but to construct something new which will impact between now and 2040. In order to achieve this goal, the TSB is harnessing the thinking of key stakeholders in the area as well as looking to research to provide original key messages which can then be used to inform a major project for 2013. The end result of this project will be the delivery of new and improved products, services and facilities in an integrated, sustainable and holistic, community-centric system of long-term care fit for the 21st century.

The Lived Experience’ report has been produced by Experience Research and Consulting Limited and is one part of the overall social and economic research commissioned by the TSB. Intrinsic to the project was deemed to be an exploration of the lived experience of a range of people, either already in a long-term care setting, working in such a setting, or being at different life stage but with an eye to what the future might bring.
Overview

The report is structured as follows:

- Section One: Provides an Overview of the work and an Executive Summary;
- Section Two: Focuses on the research – the approach, recruitment, the care homes that were visited and narratives from the time spent with participants;
- Section Three: Identifies the key messages from the research; and
- Section Four: Sets out concluding remarks, next steps and acknowledgements.

1.2 Why is this Research Important?

This part of the research required by the TSB was to be largely ethnographic in nature, capturing the voices of people, providing an opportunity for them to tell their stories and for their experiences to then inform this project. Access to older people in care settings is often difficult and presents ethical issues to be resolved both with the people themselves, the staff and relatives.

However, there is significant value in people’s perspectives on their lives as these impressions can lead us to new insights and awareness of issues and concerns not previously addressed. Qualitative research can also identify barriers that stop people living a life they might wish to live.

Radically rethinking current models of long term care and dependency has to start by placing people at the centre of future solutions. We are all familiar with the key statistics around ageing in the UK – a rapidly ageing population, with the population aged over 80 set to almost double by 2030.

The people centred research is intended to go beyond statistics and tell the personal and often emotionally moving, stories of older adults and professional carers.

The research was carried out over a relatively short period of time and is illustrative rather than statistically driven.

This report sets out key messages from the research which in turn, provide contextual understanding when identifying opportunities for future service and product interventions, to support more vibrant lifestyles and a better quality of life for older adults.

(source: [www.parliament.uk](http://www.parliament.uk), The Ageing Population).
Overview

1.3 Executive Summary

The key objective of the research was to identify the needs, wishes and aspirations of people in terms of their lived experiences, which will provide context when considering the untapped opportunities to radically rethink the provision of long term care or dependent living for older adults. The research provides a framework and a point of inspiration to enable technology providers, service and design innovators and business and community entrepreneurs to place the needs of people at the centre of new solutions.

A programme of people centred research was carried out with 10 participants. Time was spent with three key groups: people living in care homes; those living in their own homes and professionals working in care settings. People living in care homes and their own homes were between the ages of 48 and 98 and included an engineer who served in Coastal Command during World War Two, a couple who lived in Australia and France before returning the United Kingdom and a lady in her 80s who sings in choirs and leads informal walking groups (please see section 2.4 for participant narratives). This research was by necessity (time and the difficulty in accessing people in care settings) based on a small sample size but it will complement both the economic and social research being carried out simultaneously.

The research generated a number of key messages:

- A person’s own home is extremely important. People have strong emotional ties to their home and they reflect the identity of the occupier. People want to stay in their own home and maintain an independent lifestyle for as long as possible.

- Participants living in their own homes felt that the current care home system needs to change and reflect the needs and desires of people. The majority of participants did not want to enter the current care home system, only one person made a pro-active choice to live in a care home. However, people spoke about benefits associated with moving into a care home. These included a feeling of safety and security, not having to worry about preparing meals or washing clothes (or even deal with property maintenance issues), experiencing new situations and a feeling of relief amongst other family members (which may indicate that family members need support too).
Overview

- Articulating future scenarios for dependent living was difficult, particularly for participants living within the care home setting. People hinted at a more connected lived experience for future generations, continuing with their current lifestyle based around personal choice and maintaining social relationships.

- Healthy social networks are at the heart of vibrant independent lived experiences that were observed – they help to maintain meaningful lives and lead to stimulating and emotional engagement. However, it can be difficult to make new friends and maintain links with family members and existing friends when living in a care home. Good health, transport links and technology act as enablers which help to foster social networks and activities. Problems emerge when health declines or you no longer own a car or find it difficult to use public transport.

- For generations in the future, technology based products and services will be central to the lived experience. Participants outside of the care home setting used a range of online based technology services on a daily basis to communicate, purchase goods and services and to learn. In the care homes that were visited, there was very limited use of such services.

- People find it difficult to actively plan for long term care or dependent living in the future. For two participants, living in a care home the transition was sudden, somewhat traumatic, unexpected and unplanned.

- Care professionals, particularly the innovative Activity Co-ordinator at one care home are central to creating a vibrant and empowered lived experience. Care professionals have a very demanding job – which includes emotional and physical challenges and low levels of pay. Additionally, the public have a poor perception of the role carers play in society.

- Care homes need to be more connected with their local communities and even with other care homes. These connections could bring more activity and resources to the home, enhancing the quality of people’s lives.

For further detail please see Section 3 Key Messages.
Overview

These key messages will help to underpin and identify opportunities which will shape how the lived experience of dependent older adults in the future could be very different. A number of these opportunities relate to changes which can be implemented in the near future, with appropriate financial and policy support to positively alter the lived experience.
2. Research

2.1 Methodology

Spending time in the environments where services are delivered or could be delivered in the future was central to the research approach. Understanding the context and developing a rapport with participants helped to build up a rich description of everyday life experiences.

Research visits took place in care homes and the homes of participants - the familiar environments helped to put participants at ease and research materials were prepared with input from the TSB. During each research visit an exploration guide was used to maintain a conversational flow and where possible, participants provided a tour of their home environment. Broad areas were probed during the research and included subjects such as health, technology and social networks. Tools including a social network map were used to explore people's social connections and a timeline enabled us
Research

to explore a day in the life of participants (please see Appendix One for photographs of the research tools). Flashcards with images of different technologies and assistive devices were used to prompt discussions and elicit responses from participants. Research visits lasted between two and five hours. The research has been emotionally challenging with extreme moments of sadness and joy experienced as the participants shared their stories.

The interviews were recorded using an audio recorder, field notes were taken and photographs were used to document the visits. The analysis sessions focussed on reviewing each audio recording with field notes and photographs. Common themes and patterns emerged from the research and this helped to identify the key messages. Quotes in this report are used to illustrate particular points. Participants, particularly those living in care homes, found it difficult to project to the future to identify alternative models of care. This could be because people living in care homes were focussed on day-to-day living rather than on the long-term future.

As part of the research programme a limited study of relevant publications was undertaken (please see Appendix Two for a list of the reports).

2.2 Recruitment

Recruiting participants living in residential care homes was difficult and it was only through personal contacts of a TSB project member, that access was gained to these environments. It had been hoped that the study would include at least one participant from an ethnic minority group but this proved difficult to achieve. Firstly, the homes in the research had only one or two people from different ethnic origins living in them, and these residents may either not have wished to take part in the study or through a medical reason were not able to be involved. Many ethnic groups still largely care for their older adults within the family although this may well start to change in the near future as generations become more established.

There were three broad groups of participants:

- People living in care homes (aged between 80 and 98);
- People living in their own homes (aged between 48 and 80) and
- Professional carers, including a Deputy Manager, Social Care Assistant and Activity Co-ordinator.
Research

Participants were informed about the objectives of the project, how the research would be used and the format of the research visits. All participants signed a consent form and received vouchers to thank them for taking part in the research. All names of participants and care homes visited have been changed to preserve anonymity.

2.3 Care homes visited
Three care homes were visited, of differing size and offering different care options:

The Larches
The Larches is a residential care home situated on the edge of a small town in pleasant surroundings. It has capacity for 27 residents and offers a range of accommodation, a sunny living room overlooking a well-tended garden and home-cooked meals in a conservatory style dining room. The Larches specialises in the care of older people, encouraging independence as far as possible and ensuring privacy and dignity. The home is not EMI registered nor does it provide nursing care. Activities, events and outings are organised throughout the year. Residents are encouraged to personalise their rooms. The home places a strong emphasis on staff training. They have recently built additional bedrooms for residents.

The Larches is privately owned, not part of a chain and is personally managed by the owner.

Sycamore Villa
This residential care home is in a quiet residential area and offers accommodation for 24 older people, including respite care but not nursing or EMI care. The emphasis is on quality care and residents are encouraged to be as independent as possible. Most
Research

Residents have personalised their rooms with furniture, pictures, photographs etc. There is an in-house Activities Co-ordinator and annual events such as a summer fete, Christmas carols and Easter bonnet competition are organised. Sycamore Villas is privately owned by a small limited company, which also manages one other care home.

Greyfriars Towers
Set within a thriving market town, this care home offers accommodation for 49 older people spanning residential, dementia and nursing care. Each type of care is accommodated within a different section of the home but the three come together for activities and events – organised by the in-house Activities Co-ordinator. The home emphasises helping older people to maintain their life-style and independence.

Greyfriars Towers is run by a national care home provider with homes across the country.

2.4 Our Participants
Ten participants in care homes and their own homes were interviewed. These are their stories which provide a contextual background for technology providers, service and design innovators and business and community entrepreneurs to consider when rethinking the lived experience of older adults.
Research

Living in a care home
- Joan, 98
- Ron, 92
- Rosemary, 80

Living in their own home
- Eleanor, 80
- Miranda and Tom, 65
- Amber, 48

Professional carers
- Jane
- Tassia
- Abby
Joan is 98 years old, she has been a widow for over 40 years and her only child passed away from cancer when he was in his late fifties. She has been living in a residential care home for approximately two and a half years. The move into the care home was sudden and unexpected, Joan moved in straight from hospital following a heart attack and appeared to have had no choice. “I had a heart attack. It wasn’t a stroke. That happened, then hospital and I was told I couldn’t go back to my own flat…” Joan never thought that she would leave her own home and live in a care home.

Prior to moving into the residential care home Joan had a number of hobbies including painting and charity work, but she no longer felt that she could carry on with her hobbies.

Joan has a number of health issues which significantly impact on her day to day life. She finds walking very difficult, along with standing up for long periods of time. Joan also finds it difficult to hear clearly, making watching television in her room problematic. This also discourages Joan from visiting the communal lounge area as she finds it difficult to hold conversations with other people.

Joan uses a limited range of assistive equipment or technology services. In her room she has a remote controlled television,
Joan’s story

which is used on a daily basis, a radio which is rarely used, a safety alarm and telephone. She also has two walking frames.

Joan’s social network is small, friends have passed away and she only has a limited immediate family. The last time Joan left the care home for a trip out was for a meal at Easter (over five months ago with her daughter in-law). The twice weekly visits from her daughter in-law, who is in her 60s, are eagerly anticipated. Joan finds it difficult to make friends with other residents partly because of her partial loss of hearing. Joan occasionally leaves her room, perhaps twice a month she will visit the lounge and one of these occasions is to receive Communion.

Joan believes that the carers, who she refers to as the “ladies in blue” work very hard and the social interaction between carers and people in their care is very important.

However she felt that the younger carers do not spend time getting to know anything about the people in their care.

Joan’s day follows a set routine which is very structured - breakfast is served in her bedroom at 7.00am and along with supper she also takes lunch in her room. Prior to moving into the care home Joan was preparing her own meals at home. Joan is ‘switched on’, filling the time between meals by reading the Daily Telegraph and watching two television programmes in the afternoon. Generally Joan is in bed by 9pm.

In the care home Joan feels that there is lots of sitting around and that “you get out of walking...” She has personalised her room to a limited extent through the use of furniture and photographs. She greatly misses the sea view she had from the flat. There seems to be an acceptance of her everyday life situation and the focus is on the immediate present, rather than the future - “this is my age you take what comes...” The care home Joan feels provides her with a safe and clean environment.
Ron’s story

Ron who was born in 1920 left school aged 13 to work in a garage. He enlisted as soon as war was declared in 1939. “When war was declared by Chamberlain 3rd September 1939 I rushed down the recruiting office and joined up...at 19 I enlisted in the RAF.” After being demobbed in 1947 Ron worked as an engineer for 37 years for various companies in the aerospace industry and retired in 1985. Ron married and had three children, but has been a widower since 1971.

Ron has a number of health problems – he finds it difficult to walk any distance, is blind in one eye, has diabetes and an issue with his bladder. He also has a tendency to fall over, although he has managed to catch himself so far. This impacts on the quality of his life in a significant way, particularly as he gets tired very quickly. “I have to stagger about with a stick...yesterday I completed a circuit of this building. I was so pleased...by the time I got back I was knackered.”

Ron made the conscious decision to move into a residential care home as he was finding it increasingly difficult to manage at home. “Well I suppose I couldn’t literally look after myself...there comes a time when you are just physically incapable...” It was a planned move and together with a friend he looked at several care homes. These initial visits horrified him “…they smelt of urine and cabbage...
Ron’s story

It was appalling…” Following a recommendation from a friend he settled on the current care home.

While Ron feels settled in the care home it has still been a difficult period “it’s very difficult it’s such a wrench on your life...You’re not private any more. You’re queuing up for the loo. It doesn’t happen very often.” He has limited choice and control over the everyday activities which he used to take for granted, for example, when to have a bath or what to eat.

Ron was adamant that mobile phones, computers and associated services such as email and Facebook were not for him. However, he felt a degree of frustration that he could not use them. But felt that it would be too difficult to learn.

He has a large family - three children, six grandchildren and three great grandchildren.

Two of his children live in the north west of England and he does not see them as often as he would like. Ron’s circle of friends has diminished as friends have passed away, although a neighbour still visits Ron once a month.

He used to lead an active social life - Ron belonged to two bridge clubs and filled his time by going out and meeting up with friends and neighbours, pottering in the garden and spending time at a motorcycle club (he used to own a Triumph Tiger 100). Ron does not find it easy to make friends in the care home and there is a sense of loneliness. Ron does not have any interest in forming an intimate relationship and they are not encouraged within the care home environment.

He has to rely on visits from his daughters to stock up on everyday items which he used to take for granted – soap and razorblades. It is difficult to organise Christmas cards and presents and Ron decided not to send any once he moved into the care home. “You feel so trapped...I’d love to go out...to go down town and walk around all the places...the supermarket...a coffee somewhere and go down to the seaside and have a 99...”

Days follow a similar pattern and there is a feeling that they slip past. The routine is constant and to some extent this provides a sense of security. There is a sense of boredom – days are filled speaking with other residents or by spending time in his bedroom. He misses his garden, vegetable patch and neighbours. Ron recognised that the care home provides security and that someone is on hand should you fall over.

Although he has been living in residential care for just over 12 months, there are some
Ron’s story

niggling issues over the bathing routine (once a week) and menu. However, Ron appears to be happy with the level of support he receives – especially as the manager goes the extra mile by driving him to hospital appointments.

When Ron was younger, no consideration was given to planning for dependent living in the future, particularly as Ron did not think he would live until the age of 92. He has tried to protect his assets so that they can be handed down to his children.
Rosemary’s story

Rosemary is 80. She met her husband on a blind date and she has two children, who live in London, and four grandchildren. Her husband passed away unexpectedly when he was 60 and she has been a widow for the last 20 years.

Rosemary has been living in the care home for a year and she moved in after she was released from hospital. The move was very sudden and not planned for “it happened so quickly…I don’t think I was with it…” Her son and daughter found the care home. Rosemary feels that as she lives in a care home she is now less of a worry to her children.

Rosemary still cannot believe that she is now living in a care home, she reminisces about previous experiences – such as going on holiday with her husband, the homes they owned and parties they attended. Rosemary sometimes struggles with the fact that she is now living in a care home “I can’t believe I am here…I think how an earth did I leave my home…” Rosemary has personalised her room with some antiques, paintings and Chinese rugs. Although she commented “I wish it was back to how it was” (living with her husband in her own home).

Rosemary finds it difficult to walk and uses a walking frame and when out on trips sometimes has to rely on a wheelchair. Physically she is very tired, although this does not restrict the trips she goes on. Whilst Rosemary is 80 she feels that “in my mind I am 35.”

Her day is very structured and the routine is important to Rosemary as familiarity creates a sense of security. Rosemary will only watch television after 6pm in her room, she listens to the Today programme on Radio 4 and reads the Daily Telegraph. Rosemary finds it difficult to make friends within the care home environment. “I am quite solitary…I like to read my papers in the conservatory…” This is a personal choice. She maintains contact with three local friends who visit her. To entertain these friends Rosemary, working with a member of the care home team has ‘tea parties’ in her room. The carer will visit Waitrose (or Rosemary will take a taxi) to purchase cakes, flowers and a bottle of wine. This socialisation is a continuation of her everyday life experiences prior to moving into the home (which is encouraged by the Activity Co-ordinator).

Special occasions such as birthdays are important to Rosemary as they create a reason for the family – children and grandchildren - to come together. They also generate memories which provide a conversational point for the future.
Rosemary’s story

Every two weeks there are organised trips, recently they visited a SeaLife Centre and they are already talking about their next trip. These trips are important as they create positive memories and talking points. “I enjoy the outings. It’s nice to do something different.” People in the care home choose the places they would like to visit. Importantly, Rosemary felt that if she was living in her own home she would not think about visiting and experiencing these different places. Other trips include shopping and lunches with friends and family.

Rosemary has no wish to engage with hi-tech products and services such as email, Facebook or Skype. Rosemary has a mobile phone which meets her need to communicate with her family.

It was difficult for Rosemary to project into the future; she was focussed on the present day to day living and past memories.

In terms of alternative care models Rosemary felt that staying in her own home, rather than moving into a care home, would have been too difficult, she would have found looking after the property and everyday tasks as too burdensome. She thought about having a live-in carer but felt that she could not have coped with having a stranger living in her home.

Please note Rosemary did not want her photo taken and we decided not to record the interview – only field notes were taken.
Eleanor’s story

Eleanor is a very active 80 year old and before retiring she worked in the education sector and for a well known charity. She led an adventurous life, working in Africa and in her 60s Eleanor regularly panned for gold in the wilderness areas of Canada.

While Eleanor leads a very active lifestyle, she has a number of health concerns: she has lost the sight in one eye, has poor hearing in one ear, had a hip replacement and has arthritis in her hand. She has also been prescribed Warfarin and recently had a fall.

Technology plays a role in Eleanor’s life – she has an Apple laptop, which is mainly used for communicating with her friends (located across the globe), searching out information, booking flights, watching music performances on YouTube and purchasing books on Amazon. Eleanor has not owned a television for a number of years, but uses iPlayer to watch programmes she is particularly interested in. She owns a mobile phone, but it is generally used for emergency calls. Eleanor does not want a smart-phone “they all look too complicated...All I want to do with a phone is speak to a friend. I don’t want to take photographs...I don’t want to look anything up...” She has a personal alarm and key box, which friends insisted that she purchased. Eleanor has a walking stick and recognises that using mobility aids in the future could help to improve the quality of her life.
Eleanor’s story

She leads a busy social life which is at the heart of her world – she is mentally and physically active. She sings in two choirs and a music group, regularly visits art galleries and the cinema and travels throughout the UK. Only recently she had returned from a break in Italy. Eleanor leads walking trips with large groups of friends and she also helps a 94 year old neighbour with his garden. Eleanor has never been married, although she has been close on several occasions. She has no children. There is a wish for some companionship, for example, to experience Paris with.

She has a close relationship with three neighbours who live together. If Eleanor is feeling under the weather they will pop in and ask if they can do anything. Eleanor has given up driving because of her eye sight and also she found it difficult to justify the cost of owning a car. This has impacted to some degree on the friends she visits and she now relies on a friend to drive her to the garden centre. The free bus pass is extremely important “we use the bus pass all over the place...all over London”.

Eleanor lives in a three bedroom Victorian house which has a small well tended courtyard garden. Home maintenance is an issue, as unfortunately, a local handyman, (someone she trusted and who would come out to take on very small jobs around the home), recently passed away.

Eleanor has looked at moving into a retirement flat, something which is more manageable, but “they were so small...They had no outdoor access. I just felt I would be imprisoned into a shoebox”. However, Eleanor has since looked at another flat which more closely meets her needs “I did find one I quite like and I shall bear it in mind.

It was bang in the centre of town. I could walk to the pictures and things like that... it had a balcony and a garden. So I am keeping my eye on that...It had a residential warden.”

She feels that it is difficult to plan for the future in terms of the provision of support and care. “I just feel helpless. I don’t think there are any plans or any preparation you can make for this.”
Miranda & Tom’s story

Married since 1969 they have a son who lives locally. Tom has a background in farming and construction and Miranda worked as a secretary and latterly in the social care sector. During the 1970s they moved to Australia but returned after six years because of their ageing parents. After working in the UK they both took early retirement and moved to France, where they lived for eight years. They have recently returned to the UK. They live in a two bedroom ground floor flat in a small rural village.

The move back to the UK was in part prompted by several health issues Miranda has including osteoarthritis and fibromyalgia. Miranda’s health has had an impact on activities she takes part in, for example, she is no longer able to join her husband on his daily walk. Tom has high blood pressure and cholesterol levels, and wears a hearing aid.

Miranda and Tom feel that some technological devices and equipment could be used in the future to help maintain their independence. These include personal alarms through to mobility aids and even a robotic vacuum cleaner. Miranda commented “I know these are going to have to be part of my life eventually…” Both Miranda and Tom use walking sticks and feel that “mobility aids keep you in charge and give you more freedom…” and Tom believes in using devices that assist you as “there’s no point in struggling with something.”
Miranda and Tom’s story

They have a large network of connections – from close friends and family members through to neighbours and nodding acquaintances in the village. Their social network is geographically dispersed. As newcomers to the village they have already made inroads with new friends and they are about to join a gardening club and book club. Tom has a number of hobbies including gardening and sea and fresh water fishing, Miranda’s hobbies centre on cooking, making chutneys, reading and she is just about to start embroidery. As a couple they support each other. The positive social relations and activities contribute towards a sense of wellbeing.

Along with meeting up with friends, Miranda uses email and Facebook to maintain her social network. She uses her laptop to watch YouTube videos, carry out research and find out the latest news. Tom appeared to use less technology based services and does not own a mobile phone.

Tom drives and the car makes completing the weekly grocery shop that much easier. It also gives them the freedom to take multiple holidays throughout the year – they often look out for bargain breaks in the UK. Both Miranda and Tom use the free bus pass and this provides an important tool to travel around the local area.

Both Tom and Miranda have started to plan for the future in terms of remaining in their home for as long as it possible. To maintain their independence they made a conscious decision to purchase a ground floor property as they realised in the future it may be difficult to walk up and down stairs. "I know when things aren’t in place when you are old and all of a sudden you have to face up to the loss of your abilities and there’s nothing worse than the loss of your dignity...so we are on the ground level.” Village shops are accessible from the flat and they are well served by a bus route which takes them into the local town. In the flat they removed the bath and replaced it with a walk in shower and Tom has built raised flowerbeds so that Miranda can still enjoy gardening.

Looking towards the future Miranda could potentially see herself moving into a care home although she recognised that there are areas of the current care home system which need to change. “I have no problem envisaging myself in that (residential care home). But I must be frank. The way they are currently run, isn’t to me the perfect scenario for myself…” Tom could not see himself moving to a care home “the thought of having to be dependent on somebody else in a care home would absolutely fill me with horror... The thought of losing independence is horrible.”

There is a wish from Miranda that when the quality of her life declines to certain point,
Miranda and Tom’s story

she would like the opportunity of legally ending her own life.

Having to sell their own home to fund the provision of future care does not sit well with Miranda or Tom.
Amber’s story

Amber is 48 and a single mother, her daughter is away studying at university. She lives on her own in a small cottage in a coastal area and works part-time. The home is central to Amber’s life – she has personalised each room with items of furniture she has restored from purchases at car-boot sales as well as adding photographs and knick-knacks.

Over the last eight years Amber has suffered a number of serious health issues including a brain aneurysm and whilst in hospital Amber picked up the MRSA infection and C-Diff. “Now I have to survive on 22 tablets a day...that’s just to do with my tummy...” This has severely impacted on her day to day life – trips away from the home require careful planning, as she worries about the brain aneurysm.

She is also concerned about how she will look after her parents in the future. Her parents are in their early 70s and whilst they only live 10 minutes away, their wider family live over 400 miles away in Scotland.

Technology plays an important role in Amber’s life. Her father recently bought Amber an iPad which she uses every night to check her email, see what her friends are up to on Facebook, watching funny clips on YouTube, shopping online or generally...
Amber’s story

searching online. She uses Skype to keep in touch with her parents when they travel to America. “At least with the Skype I talk with them twice a week...It makes me feel like they are close by...” Amber also uses her daughter’s old laptop and mobile phone. A friend of her father helped to set up the home Wi-Fi network. She has thought about purchasing a personal alarm now that she lives on her own. Amber’s faith in technology has been tested when it does not work.

Looking towards the future Amber hopes that she will not need to use a walking stick, but recognises that she will probably need one in time. Looking at the flashcard of the Zimmer frame she commented “it’s scary...Cos I just realised it (old age) will come to all of us...” Amber felt that assistive equipment could play an important role in terms of helping her to live in her own home as long as possible. She believes that if she was no longer able to make it upstairs she could live on the ground floor of her home (as there is a toilet on the ground floor).

Amber has a network of close friends. Even though she has a number of medical conditions to manage Amber acts as a rock for her friends who have come to rely on her for emotional support. She is very close to her daughter and parents who offer her some emotional and practical hands on support. Amber has not felt like meeting a partner since becoming ill, although looking to the future she would like to meet someone for the companionship. “It’s not about the sex as you get older. It’s more about the companionship and everything...I would like to meet somebody... Sometimes it would be nice to be taken care of.”

Looking at support to promote independent living Amber was concerned for people who do not have the support of family and friends. Amber’s perception of the care home system was not positive “I think when you get to a certain age as well, especially if you have got an illness or dementia you’re not going to know who is talking to you or anything. Basically you are a slab of meat. You think of all of these poor people. No I would hate to be in a care home.” In the future she does not believe that she would like a stranger coming into her home to provide support. From Amber’s perspective the current system does not meet her aspirations or needs. She believes that people (older adults) will survive for longer if they actually lived in their own homes. The only element of the current provision which offers some limited potential are warden assisted living schemes.
Amber’s story

Amber wants her daughter to inherit her home; and is resistant to the idea that it will be used to fund her care. “But my house won’t pay for it, that’s for sure...I think that’s wrong how they do that...”

Dependent living in the future does not fit into Amber’s financial planning.
Tassia’s story

Tassia works part time as a Social Care Assistant – she mainly covers the night shift. Tassia has only been working in residential care for three years, but is driven and has an aspiration to manage a care home. Prior to working in the residential care home sector Tassia was an assistant manager of a restaurant. Training opportunities are seized by Tassia as a way to progress her career.

“'I am just completing, I've only got a month left of my diploma in health and social care. When I've done that I can go on and do a team leader role or a management course if I wanted. In the long term I can be a manager of my own care home”

In the same way to Jane, a professional carer, she feels particularly valued when people in her care say ‘thank you.’ The occasional thank you goes a long way to creating a sense of being valued.

Touching on the qualities of a good carer, Tassia believes this is about listening to and respecting the independence of residents. Tassia feels that news reports unfairly shape the public’s perception of care homes.

During the night shift Tassia has responsibility for 22 people in her care, who have different needs. “At one extreme we have clients who do everything themselves - they need no assistance whatsoever, they just like the fact that they get their meals cooked for them and
Tassia’s story

there’s company around… Till the odd client who needs a lot of help…maybe with eating, obviously with going to the toilet, bathing and showering…”

There are some low points associated with the job and these centre on the night shifts and pay. “I don’t think it is good enough…I suppose for what we do and what we are here for…At the moment everything is going up…I think the minimum payment should be £8 an hour now days…”

The night shift feels less stressful than the day shift and Tassia’s shift starts at 9pm and ends at 7.00/7.15 the following morning. Some people in her care need to be monitored more closely than others including a person with diabetes “she has to have insulin…she gets watched overnight…We usually do her blood sugar level…”

Similar to the care home where Jane works there are limited high tech devices which are used within the home. Tassia feels that hi-tech products could be leveraged to help improve her working day. This includes developing personal care dashboards, which could highlight key information about each resident rather than having to use a paper based system, which is not that accessible. “Trying to flick through 10 pages of erm…it could all sort of be there in one touch.” This could also include information on important dates such as birthdays.

A common thread to emerge was to encourage more communication between residents and family members, perhaps by introducing a communal PC and using Skype with video. “A good idea for friends and families…that’d be brilliant for clients to talk to their families. We have a couple of clients where their families live in France so they don’t see them very often.” It is about giving the residents the choice as to whether or not they would use the technology. Among people in her care she recognised that there is limited interest in this type of technology, however, she believes future generations will ask for a connected lived experience.

In the longer term Tassia recognised that technology will play an increasing role in the care home environment but the human interaction between carer and resident will still be central. “It’s just the (human) interaction and that…listening…just sitting there listening…”

Care homes offer sense of security for some residents and opportunities for social interaction. “On the other hand you get some who come in and are happy to have others around. They are not on their own from morning to night and they felt that it’s nice to have people around all of the time even if it is staff. At nighttime there’s someone there to answer a bell, checking on them every 2 hours to make sure they are ok.”
Jane’s story

Jane is a Deputy Manager of a residential care home where she has worked for ten years. The care home sector was not her first choice of career; previously she worked as a waitress.

As a career choice Jane feels that people tend to have a negative impression about working in the sector, which is reinforced through the shift pattern of working, low pay and limited resources, particularly staff provision in the care home itself. There is a high turnover of staff. “The massive turnover you get in...people come in and think they can do it...don’t like it and leave.” Low pay is an issue “I don’t think it’s great money to be fair...it’s the normal six something an hour they get...” This high turnover of staff impacts on the quality of care provided, particularly in terms of relationships developing between carers and people in their care.

Jane feels that it takes a certain type of person to successfully work in a residential care home. The key to providing care Jane believes centres on “having that little bit of respect... you have got to spend time to listen...that’s what they (the people in my care) want...” At the same time little things – a ‘please’ and ‘thank’ you from people in Jane’s care helps her to feel valued.

There are over 20 people in Jane’s care. Her day follows a set routine and she spends most of the day on her feet. Mealtimes
Jane’s story

are focal points in the day – breakfast is served in the bedrooms, residents who need assistance are then helped with washing and dressing, mid morning coffee is served and activities such as board games and quizzes are programmed in before lunch.

Lunch is served at 12 noon in a communal dining area and any medication which is required is given. Time in the afternoon is dedicated to updating care records and checking that the laundry has been completed. Afternoon tea and cakes are served at 3.30pm and supper is served between 5pm and 6pm. Jane then spends the following hour clearing tables and completing paperwork before handing over to the evening shift at 7pm. Sometimes she finds that her days become tedious. Jane works 8 days on followed by 1 day off, then 2 days on and the weekend off and as a Deputy Manager can also be on call. Jane finds that her job can be quite stressful and emotionally challenging “You are dealing with all different emotions all of the time....there’s a lot of emotions...you have got to deal with...it is quite stressful.”

Jane feels frustrated that she cannot find enough time in the day to spend time talking with people in her care. She believes this interaction is key to enhancing the quality of the lived experience. Jane commented “you have to brush them off a little bit because you haven’t got the time to talk to them...” If Jane had more time to dedicate to one task it would be “spending time talking with them...you haven’t got time to chat...”

Some assistive devices are used within the care home environment. Bathing seats are used, walking frames are available for residents, a chair lift is used, commodes are available, a hoist is available but very rarely used. Devices such as smart phones and tablets are not used. However, Jane could see immediate uses for some high tech devices in the care home environment particularly technologies which could improve connections between people in her care and their families; internal communications and technology to help improve the efficiency of Jane’s day.

Jane believes that improving connections with family members via video communication e.g. Skype would help improve the lived experience of residents and help to reassure family members that their loved one is being cared for. “It’s quite nice for the family member to see them....How’s my mum looking today?...It’d put their mind to rest....” Jane recognised that encouraging people to use services such as
Jane’s story

Skype will be difficult. The real opportunity she feels is with future generations who have used services such as Skype as part of their daily lives.

There are an abundance of care files to look through to check the medical history and the specific needs of people within the care home. Jane believes that a device such as a tablet would enable her to access this type of information quickly and it would also help when recording and administering medication without having to review paper case files. “Anything to make our time better spent on the residents and to make our lives and paperwork a lot easier…” Jane feels using a tablet will help her to save time during the day – allowing her to spend more time with people in her care. Jane sees a role for technology products and services, but she strongly believes that the human support (both emotional and physical) provided by professional careers will remain central to improving the lived experience.
“We have to carry on that life...this is an extension it’s not where life stops...it has to be an extension...I had a lady who used to have tea parties in her house...so she now has it in her bedroom...with her friends....I am a facilitator. A co-ordinator should not just be someone who is a nice person who comes in and plays scrabble...that’s not the job...the job is like to be...a facilitator of lives. Lives need to continue and that’s what we are doing here...”

Abby has been working in the care sector for a number of years. She started a degree in nursing but found that it did not meet her needs – there wasn’t enough time spent with the patients. Abby did not finish her degree and started to work in the community with older adults through to people with alcohol and drug dependency issues, some of this work was carried out on a voluntary basis. “Being a musician I went in to different places voluntarily...playing the piano and singing...then I kind of thought well the children are a bit older and I could do with working full time...” Abby has now been working in the care home as an Activity Co-ordinator for two years. Her role is not functional task orientated, it focusses on providing a holistic, people centred care package, which takes into account the physical, social, emotional and spiritual needs of adults. For the first two weeks after arriving at the care home Abby will spend time every day with that person to ensure that she understands their specific needs, wishes and
Abby’s story

aspirations. Abby recognises that the transition into a care home can be traumatic for some people.

Abby believes her background has equipped her with skills and experiences which are essential in her role as an Activity Co-ordinator. “What I have, which makes me different to other co-ordinators out there is that I have a scientific knowledge which underpins my creativity....I have a science knowledge base of holistic care, person centred care and evidence based practice which underpins what I do. So I am not just a nice person trying to make people happy and I think that is really why I am being really successful in this role....” Abby feels that there is a need for a recognised, specialist qualification which should be available for Activity Co-ordinators as they play a central role in maintaining the lifestyles of people once they transition into the care home environment. There is a feeling that the System in the UK does not take the role of Activity Co-ordinators seriously enough. Abby described how in care homes in the USA that Activity Co-ordinators are on a par with the senior management as their role is critical in maintaining the lifestyle of people.

Whilst Abby has responsibility for the well-being of 40 people she is paid just over the minimum wage. She has an aspiration to become a regional Activity Co-ordinator.

Looking to the future there is a desire for care homes to integrate Activity Co-ordinators within the overall service offer.

There is a belief that older adults receiving care can contribute to the care system itself and the wider community. Abby emphasised the importance of maintaining links with the community and in particular local schools.

Abby is forward thinking and innovative. She is about to start a project to turn a small area within the care home into a bistro, where small intimate groups can gather to talk and eat together.

Hi-tech products and services currently do not play a significant role in the care home environment. Abby feels there are opportunities to use hi-tech based products and services. With the right support she would set up an internet café within the care home itself. This would enable adults to learn how to use online technology services together. Although Abby feels that older adults can sometimes find it difficult to use a keyboard or mouse so the solution would be to provide every person with an iPad (touch screen and voice activated controls).

Individual tablets could be used to store the person’s care plan and digital photos and
other memories, and they would be used to go online and search out information of interest. Tablets would also help to reduce the amount of paperwork and improve working efficiency. “We have so much paperwork...if each person had an iPad in their room which contained everything we would go paper free....everything about that person (would be on the device)....”

On another level in the future she feels that adults of her generation (Abby is 35) will demand a more connected lived experience. “In the future...my generation I am going to want to be on Skype every five minutes because that is how I keep in contact with my friends in Canada or my family in London...we are on Skype.”

Abby summed up the importance of providing people with choice, dignity and empowerment and described these elements as the "essence of person centred care."
3. Key Messages

After the qualitative data from the research was analysed and synthesised, a number of key messages emerged which offer scope to enhance and rethink the quality of the lived experience for older adults.

They highlight the needs, wishes and aspirations of the people who were interviewed. There is a degree of overlap between the key messages - a common thread emerged which focussed on placing people at the centre of change.

A fresh look often calls for radical solutions, but some of the key messages point to small, quick win, incremental changes which will help to reshape the lived experience of older adults in long-term care both now and in the future.

The key messages which emerged can be placed under seven broad headings:

- Home Sweet Home
- The Caring Experience
- Looking to the Future
- Keeping Up
- Hard Ware, Soft Ware and Home Ware
- Planning for My Future Self
- The Caring Profession
3.1 Home Sweet Home?

The home is my hub

Journeying through participants’ homes helped to emphasise the importance of the home environment. Participants have a very strong affinity with their home environment. It provides a secure space, it acts as a hub for social interaction, it is an asset to be protected and passed on to children. “My house won’t pay for it, that’s for sure...I think that’s wrong how they do that...”

The home has strong personal memories either directly associated with the physical building, past events or through artefacts within the home. Homes are uniquely personalised spaces through decoration, furniture and the collection of objects. The home is a manifestation of the self; it reflects the personality and identity of the resident. Participants were concerned about maintaining their home – from the fabric of the building through to the day-to-day housework.

Miranda commented “I do find the vacuum extremely difficult...in the future housework is a point that will need to be addressed...” This also included being able to find a trusted ‘handy person’ to help out with maintenance around the home. Other concerns included being able to move between the ground and first floor if health problems develop in the future and being able to continue gardening.

Participants aspire to remain in their own home, a familiar environment, for as long as feasibly possible. There was one example where a couple in their 60s, who live in a ground floor flat, have started to adapt their home by removing the bath and installing a walk-in shower and installing a raised flowerbed in the garden. They recognised
Home Sweet Home?

that further changes are required “changes will definitely have to be made in the kitchen... it needs to be made more effortless...to make cooking easier...Now I have to bend double...”

Transition moments are difficult

Throughout life we have a number of transitioning moments for example: leaving home; starting a new job; purchasing the first home; getting married; having children; getting divorced. Transitioning to a dependent lived experience is another of these moments, in some instances this can impact on the persons’ self-identity.

The transition into the care home itself can be very traumatic and unexpected, with limited support during this moment of change. “It was so sudden that was a dreadful thing leaving my bits and pieces. Goodness knows what has happened...half of them went to the tip....” Participants left the familiar including close neighbours then entered the unfamiliar, where they may not know anyone and this can be very traumatic causing additional confusion and stress. Participants had to learn about living within a totally new system, where people become the receivers of care.

A carer commented “a lot of people when they come in are worried, they are nervous. It’s somewhere completely new to them,” she continued that the time they spend together is very important.

There are few resources which can be called upon to alleviate the reported stress and issues surrounding this moment. There is a need to support people going through the transitioning period.
3.2 The Caring Experience

Perception of the care home system

There were strong signals which suggest that expectations and perceptions of the care home system are low and that the system cannot meet the aspirations for a high quality and active lived experience. This was evident when speaking with Tom, Miranda and in particular Amber (people currently not living within the system). “The level of care is not good...It’s not value for money. You don’t really get out of them. I think people would survive longer if they were in their own homes. I’d never want to go into one. Never. At the moment I am thinking of my mum and dad and I wouldn’t put them in a care home either...”

However, the reality reported by participants living in care homes was different. Whilst there are some issues, focussed on choice, participants living in residential care reported “we are well looked after...fairly well. There’s good food...everything is kept nice and clean.” (although clearly this view is shaped by the care homes we visited).

The care system also allowed people to experience new situations which they would not have otherwise experienced. There were some issues reported which centred around lack of choice, the structured daily routine come and get them out of bed...to get their breakfast and come back at 6 and rush them off to the toilet quick...clean them up if they have had an accident...then chuck’em into bed and they have got to stay there...”

There was also concern about the quality of care provided by service providers who visit people in their own homes. “What must it be like for people who wait for somebody to...”
(which can be very functional, task orientated) and the physical design of the homes themselves.

The care homes we visited played an important role in the provision of long term care. One participant spoke about the look of relief people can experience when they moved into a care home. “I’ve seen the look of release on people’s faces after the first week of being in care...all of these worries have simply started to dissolve away....”

**Spaces which encourage social interaction and create memories of home are key**

Social spaces within the long term care setting were not always intimate, in some homes communal areas were often large open spaces which did not lend themselves well to one-on-one conversations or privacy. In the communal lounge area, residents with hearing difficulties found it problematic to watch television and to hold conversations which lead to frustration and increased isolation. There were limited opportunities to personalise space and create that ‘homely feeling’ within the care home environment. There is a need to create small social spaces which encourage socialisation and provide opportunities for individual discussions. This is being addressed in a care home we visited.

**Shopping is very difficult**

Shopping is part of everyday life. However, a resident commented that he has to wait until his daughters visit before he can purchase essential items such as razors, something he had previously taken for granted. He is now dependent upon his daughters for basic items.
The Caring Experience

Encouraging independence is very important and a professional carer commented this could be maintained in part by introducing a shop, perhaps, a pop-up shop within the care home itself. One care home works with a clothing company whereby the company visits the home so that people can purchase clothing – almost like a pop-up shop. Shopping whether physically or online can help to maintain independence.

The rhythm of life and active lifestyles are difficult to maintain in the care home environment

The rhythm of daily life changes when you move into a residential care home. Structure and routine replaced opportunities for spontaneity (although in Greyfriars Towers this is being addressed by the work of the Activity Co-ordinator as maintaining lifestyle choices are seen as central to maintain a vibrant lived experience).

The daily flows of Miranda’s, Tom’s, Amber’s and Eleanor’s lives, which help to create meaning in their lives, could not be accommodated within the residential care homes we visited. There is an aspiration amongst participants outside of the care home system to maintain their lifestyles – to continue going out with friends, making new friends, experiencing different situations, gardening, attending choir, visiting the cinema and going on holiday. They do not see why these lifestyle choices should stop once they transition into the next stage of their life.

People in care homes are an untapped social resource

Residential care homes are home to a wide range of people from former engineers through to doctors, mechanics, teachers and nurses. This is an untapped social resource, the wealth of professional and life skills do not appear be used.

These professional and life skills help to create the self-identity of people. They represent important periods and memories. These should be maintained as they also act as points of reference in the person’s life and conversation starters.

Memories are stimulating and could be maintained through memory books, one-on-one conversations with people who are interested and talks with members of the local community.

A professional carer spoke about links with local schools (which encourages intergenerational sharing of experiences).
The Caring Experience

The payment system is thought of as unfair

A common thread emerged which centred upon a perceived unfairness of the current system of payment for care and in particular the way that homes are sold to fund long term care. This was a very emotive subject. “We want to keep this for our son and make sure he gets it... This may sound dreadful but I think we are going to make sure we haven’t got enough cash so that either of us comes below that level so that we will get some help with fees, with care fees. We are desperately hoping in some way or another that we don’t have to have this small property of ours waiting for the government to take...”

There is also a feeling that value for money is not being delivered by the residential care system. The relationship to some degree is thought of as transactional which to an extent emphasised that people in care are receivers of support rather than active participants.
3.3 Looking to the Future

It is difficult for people to articulate a vision for the future

There were some signals which offered an alternative and hinted that some forms of long term care in the future may not be delivered within the traditional residential care home setting. However, people, particularly those currently within the care system, found it difficult to articulate what the future provision of long term care would entail. For participants within the care home system this could be because they are focussed on day-to-day living rather than necessarily thinking about the future itself.

For people living outside of the care home setting and professional carers there is an aspiration for new alternative models of long term care. It was felt that for future generations this vision could centre upon a more (tech) connected lived experienced as their expectations and needs will be very different from the generations of people currently within the care system.

The rhythm of life and active lifestyles, of people that were outside of the care home setting, is difficult to maintain in the care home environment. As far as possible it was felt that the lifestyles of participants (meaningful relationships and friendships, meaningful activities, self identity and active daily lives) living in their own home should be maintained within the care home or as they transition to dependent living.
3.4 Keeping Up?

**Social connections and activities give meaning to life**
As you age social networks may become smaller due to losing friends and family, moving to a new place (perhaps sheltered accommodation) and a decline in mobility and/or general wellbeing. Multiple social connections helped to maintain a higher quality lived experience – there is a need to maintain these relationships as they also give meaning to people’s lives. Being able to go shopping, visit family or friends, chat with neighbours or watch a film at the cinema helped to reinforce personal choice and independence and reduced social isolation. Relationships and activities among participants give meaning to life and everyday living. Some of the participants were looking for companionship rather than a physical relationship. “I would like to have...it’s not about the sex as you get older. It’s more about the companionship and everything...I would like to meet somebody...”

Taking part in social activities helps to maintain and increase the size of participants’ social networks. Social connections generated reasons to take part in activities, leave the home, experience something new and provide support to individuals.

A common theme reported was that face-to-face interaction for participants was crucial in maintaining a high quality lived experience. There was a desire among participants within the care home setting to spend time with their families and maintain relationships with friends outside of the care home itself (as participants did not find it easy to make new friends within the care home).

**Making friends in care homes can be difficult**
As noted above it can be difficult to make friends in the care home environment and intimate relationships were not encouraged. A participant with physical health issues found it difficult to leave their room and this impacted on the opportunity to form social relationships particularly as “it’s not really suggested that we meet in other people’s rooms...the only place they think is available is the lounge and I can’t talk in the lounge...I can’t hear if there’s any other chatting going on...” It also should be noted that people visited in the care home setting were not necessarily looking to make new friends. Day to day living was inclined to take over their lives.

**Transport, technology and good health act as enablers**
Transport was a key enabler in terms of maintaining social networks and taking part in activities, particularly in terms of the car and free bus pass. There was a wish among participants to maintain use of their own car...
Keeping Up?

as long as possible as this facilitated everyday life activities. Taxis were viewed as expensive and due to medical conditions it was not always feasible to use public transport. There was a sense of a new dynamic in social relations once participants lost the use of their car. In some instances participants suddenly had to rely on friends.

“I am reliant on him to take the old printer to the YMCA depot...he will come and fix that and take me somewhere...to a garden centre to go and get plants...”

Technology, including telephony also helped to maintain social connections particularly if was difficult to physically meet up and the role of technology used for communication is likely to increase in the future.

Our research showed that people often have complex health conditions and these impacted on the lived experience. Eleanor reported finding gardening difficult due to a back issue, Ron found it difficult to walk around the residential care home (and he was physically very tired) and Miranda could no longer join her husband on his daily walk due to health issues.
3.5 Hard Ware, Soft Ware and Home Ware

Appropriate technology products and services have a role to play

The majority of participants had a lack of general knowledge concerning the range and type of high-tech devices, products and services that are available. Older people in care settings were familiar with landline telephones, mobile phones and televisions with remote controls. They accepted these forms of technology quite happily and on the whole do not need a great deal of back up support to maintain their connections with these devices. However, there was very limited interest within this group for the use of hi-tech products and services to help improve the quality of their life (which to some extent is explained by the unfamiliarity of these products and services).

Professional carers and people outside of the care home setting spoke about the role that hi-tech products and services could play
Hard Ware, Soft Ware and Home Ware

both in terms of improving the quality of the lived experience of older adults and the working day of professional carers. This primarily centred upon improving communication between people, their friends and family, using the internet to purchase goods and services and using the internet to learn and access information, for example about medical matters or travel needs. Appropriate technology helps to maintain networks of social connections alleviating loneliness and improving the quality of the lived experience by empowering people.

It was largely recognised that tomorrow’s older adult will require a connected lived experience to meet their expectations.

However, the research emphasised that technology cannot replace face-to-face human interaction where people maintain eye contact, can hold someone’s hand and see a smiling face. “It’s just the (human) interaction and that...Listening...just sitting there listening...”

Technology can help to free up time for professional carers

Professional carers’ aspirations centred upon using technology products such as tablets and services like online organisers and databases. This would improve the professional carers’ working day in terms of freeing up time available and making it easier to share information between different team members. The underlying driver being to increase the face-to-face time carers can spend with residents in their care. Carers strongly believed the time they spend speaking with people in their care was central to improving the lived experience. Jane felt that “giving that little bit of time to make them feel special. Just that little bit of communication makes such a difference...”
Hard Ware, Soft Ware and Home Ware

There are barriers to adopting new technologies
Eleanor aged 80, uses an Apple laptop and recognised a divide between older people who use computers and those who do not. “People who haven’t got computers and don’t know how to use them are going to be very very severely handicapped...most things are going to have to be done online...and I think people who don’t know how to operate smart-phones and so on are going to be at a disadvantage i.e. the older generation...they (older adults) haven’t got the training the kids have in school now. They have got to start from scratch to pick up all of this... things like buying tickets for flights will have to be done online...they are getting rid of shops and things...a danger for old people to be really left behind...”

There were feelings of frustration in terms of not being able to use some technologies. “I wish I could use some of this stuff so I could be in-touch with my family...What annoys me if I was given the plans and tools I could build an aeroplane. Literally a small aeroplane...But bloody clueless. I feel really left out. I couldn’t possibly sit through a course these days...”
3.6 Planning for My Future Self

**People don’t expect to live in a residential care home**

Overall there was limited early planning among participants to prepare for the future lived experience in terms of care and support provision which may be required. The underlying issue is related to behaviour change - encouraging forward planning and providing support to think about the future lived experience.

The research suggested that people living in care homes did not expect to spend time in these environments. “I thought I should live and die in (my) home...” The move into a care home could be sudden, unexpected and traumatic. Participants within the care home setting did not speak about alternative solutions at the time they moved into the care home. For two participants the move into the care home setting was unexpected – resulting from a period of hospitalisation.

Only one participant made the choice to move into the care home setting when he found it difficult to cope on his own.

**Unexpected wider macro changes can have significant impacts**

Even after you have made an active decision to plan for care in the future this can suddenly change because of unforeseen circumstances. “I always saved hard...Investments were very good. But now they are really going down the drain. The capital is diminishing rapidly...Every now and then I get worried. That was what I was saving my money for to get good care to put myself possibly into a private home...though apparently they are not as good as they used to be...I do worry about. But then what can I do about it? I’ve tried to save money for it but the money is going...”
Planning for My Future Self

Choice - planning for the end of life is a core element of the lived experience

Participants recalled moments about their lives from childhood activities through to early adulthood, important moments such as a wedding and later life. They recognised there is an ending, but that there is limited choice associated with how life ends.

This was a very difficult and emotional area to explore but some participants spoke about the end of life, it was not a taboo subject. "you’d be amazed how many people in here believe in suicide pills...euthanasia...I’d welcome it... The human body wasn’t designed to last 90 years. Let’s face it. Very bad design... no back up plumbing... they talk about it (dying) quite openly... (and refer to the care home) as God’s waiting room."

It was felt that there should be the choice when to end your own life particularly as the quality of life deteriorates.

The end of life should be considered as an essential part of the lived experience and not remote and separate. For some participants this choice was very important. “Once it became obvious to me that my quality of life wasn’t particularly good and that my life was totally dependent on other people... then I would like to have a choice of dealing with my future... I would like to be given the choice of ending my life if my mind was intact... and be able to do it legally and prefer not to have to go abroad to do that...”
3.7 The Caring Profession

The time spent in residential care homes was limited. The frontline staff we spent time with were people focussed, dedicated, passionate and enthusiastic about their jobs. For some people caring professionals are key to the delivery of a positive lived experience.

**Working as a carer is very challenging**

Carers face a number of challenges: low pay for a job which carries significant responsibilities; negative public perceptions about the sector; working with limited staff and financial resources; a high staff turnover and dealing with upset family members and working through very emotional periods. “You are dealing with all different emotions all of the time….there’s a lot of emotions…you have got to deal with…it is quite stressful.” The job is also physically demanding.

**There is limited collaboration between care homes**

There appeared to be a lack of interaction between different care homes and limited opportunities for active collaboration, sharing of experiences and ideas and learning from each other.

**Human contact – spending time with people is key**

It was felt that one of the most important elements of the carer’s job was spending time talking with people in their care. The day can be time pressured and finding these moments is very difficult. Products, services or systems which can increase the moments of interaction are central to improving the quality of the lived experience – helping the carer to understand the needs and aspirations of people in their care. “It’s about...
The Caring Profession

spending that one-to-one time getting to know them, their likes and dislikes. Having that personal touch that they can come and talk to you about anything.”

Activity Co-ordinators
A number of tasks within the care home environment are quite functionally orientated on basic needs – helping people to get dressed, preparing meals and washing clothes. This helps to reinforce the sense of dependency. A key role is performed by the Activity Co-ordinator who is responsible for helping to provide a holistic lived experience which includes social and emotional wellbeing and maintaining lifestyle choices. As Abby, the Activity Co-ordinator pointed out “I do see myself as a bit of a concierge...” The importance of this role does not always appear to be recognised. Positive attitudes and working practices within care homes are also influenced by the management team.
4. Conclusions and Next Steps

4.1 Concluding Remarks

Spending time with participants enabled us to learn about their lifestyles. For people who lived in their own homes it appeared that their lifestyles were often busy with everyday activities ranging from meeting up with friends, doing housework, preparing a meal, through to taking holidays or going out to work. The lifestyles were complex, but they were based upon personal choices. These are the lifestyles which participants would like to maintain if they transition from independent to dependent living. The lifestyles that were observed in care homes were very different – the world of participants appeared to have changed radically – becoming diminished and narrow.

Future scenarios for lived experiences need to be based on the needs, wishes and desires of people. People (from different age ranges) should have a say in creating new models of care, appropriate services and products which will be so appealing that they fly off shop shelves.

Technology will have a greater role to play in future as the expectations and lived experiences of future generations will be built to some extent around their everyday use of technology based products and services.

While it is recognised that this is the beginning of the RLTC programme and that the key messages are based on a small sample size, the research hints at and provides guidance and a framework for new future lived experiences which reflect individual lifestyle choices.

Finally, when thinking about the future perhaps the words of one participant should be remembered: “Every now and then I get worried. That was what I was saving my money for to get good care to put myself possibly into a private home...though apparently they are not as good as they used to be...I do worry about. But then what can I do about it? I’ve tried to save money for it but the money is going...I have no family at all...So nobody is going to look after me. So I don’t know who is going to look after me really...”

Eleanor, aged 80

4.2 Next Steps

- There is strong merit in conducting a longitudinal or ‘tracking study’ to understand the lived experience of a wider range of adults, professional carers and the impact of ageing which could inform how vibrant communities of older adults can be created.

- A participatory and co-creative approach to designing future solutions is essential. As part of this project a sounding-board
Conclusions and Next Steps

made up of people involved in this research (or similar people) would provide invaluable feedback as challenges are developed. A sounding board would help to ensure the needs, aspirations and wishes of older adults are being taken into account. There is a need to recognise the people we are designing solutions for are the ‘experts’.

4.3 Acknowledgements

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Appendix One – examples of research tools

A day in my life

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Appendix One – examples of research tools
Appendix Two – background documents

Age of Creativity – One-stop shop website for people working creatively with older people (2012) http://www.ageofcreativity.co.uk/


Find me Good Care – Social Care Institute for Excellence (2012) http://www.findmegoodcare.co.uk/


The Ageing Population www.parliament.uk
Appendix Two – background documents


Shallow dive exploratory people centred research with older adults and professional carers