Travelling well with dementia

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1. Executive summary

Upstream was launched to develop training for mobility service providers based on the insights learned from people affected by dementia. We have achieved this by developing:

A **methodology** for engaging with people, using creative methods to encourage conversations about mobility and capture insights that emerge.

The **Upstream Lens**, a training tool that collects individual travel experiences into broad challenges that people affected by dementia can face.

**Training workshops** that can help mobility service staff to understand the impact of dementia in a service context.

**Shared experiences** - training formats that bring mobility service staff together with people affected by dementia to experience a service, travel and learn together. This can lead to improved confidence to travel among people affected by dementia and service design based on lived experience. A **film** has been made based on one of these experiences.

**Dissemination and sharing** of Upstream learning through our website, our own national **conference** and presenting at national and international conferences. Upstream has also featured in national policy and has a recognised unique focus on mobility and dementia.
2. Introduction

“If I didn’t have coping strategies to remain independent and mobile I’d be very lonely and soon sink into depression. Travel brings normality to an often abnormal life”

Wendy Mitchell, recording a Dementia Diary

People affected by dementia have a right to retain their independence, to inclusion and participation in their community. This, however, will often mean getting out and about and travelling. The sensory and cognitive challenges of dementia mean that people can find travel and transport daunting. It can be particularly noisy, busy and disorientating for people with dementia, especially with the added challenges of its time-sensitive nature. Difficulties with journey planning, fast-changing technology, challenging travelling environments, lack of service integration and staff with limited awareness of the needs of people affected by dementia can become barriers to remaining mobile and connected.

If the growing number of people affected by dementia are to maintain their independence, then transport and related service providers need to understand these challenges and respond by developing products and services that lower barriers to travel.

This will require a new, more inclusive approach to transport service design, underpinned by education and training that not only provides an understanding of the challenges of travelling with dementia, but also provides a framework which supports service providers to make changes that will enable people to remain mobile and connected. This process must be informed by people affected by dementia, allowing them to share their travel experiences and ideas for making products and services more enabling. However, opportunities for them to influence or contribute to training or service improvement are rare.

Equally, mobility service providers have vast, collective experience in delivering travel and transport services, with a strong focus on customer service. Their staff may also have their own personal experiences of supporting people with dementia - personally and professionally - that they wish to share. These, informed by their own professional expertise, can bring an added dimension to training and solution development. Service providers want to make travel services people-centred but are unlikely to have processes in place to work with, and learn from, people with dementia to understand their travel challenges.
Upstream therefore launched in March 2016 aiming to:

- **Work with people affected by dementia** to understand the challenges they face when travelling and gather insights for mobility provider training and service design.

- **Develop and deliver training** that is based on first-hand experience of travelling with dementia and that values and incorporates the lived experience of trainees themselves.

- Provide a **clear pathway** for service providers to build dementia awareness, develop a better understanding and to deliver people-centred, dementia-aware mobility.

We have been working across Scotland. In **East Lothian**, the focus of our work is the North Berwick Local Area Partnership’s Older People’s Network, an open group of local people and organisations aiming to make the region a good place to live and age. We have run workshops, worked with memory skills groups and day centre residents, feeding our learning into Local Area Partnership discussions.

In the **Western Isles** we are working with the Dementia Friendly Community project at an Lanntair and Alzheimer Scotland in Stornoway as well as with local transport contacts. In addition to many conversations with groups and individuals affected by dementia in the Stornoway area, we have held several workshops with Stornoway airport terminal staff including a dementia friends sessions delivered by Alzheimer Scotland.

Upstream is also working with Aberdeen Council for Voluntary Organisations and Alzheimer Scotland in **Aberdeen** as well as with local transport contacts. We have facilitated workshops with the Positive Dementia Group which includes people affected by dementia, carers and the range of professionals supporting them.

Upstream’s work reaches beyond transport. A journey involves many steps and services including transport planners, designers, web developers, retail services, ticketing, luggage handling, security… the list is extensive. We therefore refer to **Mobility Service Providers** in an attempt to keep our approach broad and to encourage the range of services involved to recognise their role and responsibility in making travel inclusive.

Equally, while it is important for people with a diagnosis of dementia to continue to travel and remain mobile and connected, the people that support them and travel with them also face travel challenges and are equally at risk of becoming isolated through reduced mobility. We therefore refer to **people affected by dementia** in our work to ensure that the wide range of voices involved are heard.

This report focuses on our activities in 2016 and outlines initial thoughts for the future. A full proposal for 2017 and beyond will be presented in a separate document.
3. Policy Context

Transport is becoming an important topic in dementia care, while travelling with hidden disabilities is becoming an emerging interest in the mobility world. This is being driven, in part, by a widespread interest across the transport sector in ‘Intelligent Mobility’ and ‘Mobility as a Service’ which both hold, at their core, a focus on users - in terms of needs, requirements and experiences.

For example, during the course of Upstream’s first year:

The World Health Organisation’s Draft Global Action Plan on the Public Health Response to Dementia (2017 - 2025) called for Member States to ‘…Develop programmes … to encourage dementia friendly attitudes in the community and the public and private sectors that are informed by the experiences of people with dementia and their carers’. One of their suggested target groups is transport.

The Scottish Government launched its Accessible Travel Framework outlining its commitment to support and enable people with disabilities to travel and for them to be ‘…more involved in the design, development and improvement of transport policies, services and infrastructure.’

The Civil Aviation Authority (CAA) published guidance for airports around the UK for providing assistance to people with hidden disabilities. Prompted by the European ‘Passengers of Reduced Mobility’ Regulation EC1107/2006, the CAA had undertaken research that suggested that many people with hidden disabilities lack the confidence to travel. The guidance (CAP 1411) includes calls for airports to focus on ‘Information and communication prior to travel and at the airport’, places ‘a substantial emphasis on staff training’ and urges airports to set quality standards. It recommends consulting ‘regularly with organisations representing people with hidden disabilities and also individuals themselves’.

The first phase of development for Upstream during 2016 has therefore been timely.
4. Barriers to mobility

We have learned about a range of barriers that people affected by dementia face when travelling. Our discovery methods are described in section 5. Some of the insights we have gathered (in quotes) can be broadly grouped into some key areas to address:

4.1. People lose their confidence to travel

People affected by dementia have told us that poor experiences have dissuaded them or even deterred them from travel. Knowing that a journey will be successful, being able to plan with confidence, is key. However “purchasing tickets is confusing - some discounts are only available bought before - machines are confusing” and “differences in fare structures in same town / different tickets - causes confusion”. Planning connections between different transport modes can be a challenge, particularly when booking complicated itineraries.

During the journey itself, “reserved seating on trains is confusing”. People affected by dementia are less able to respond quickly to the speed of travel, wondering why stations “announce platforms JUST before train leaves/change platform”. They can feel under pressure “being pushed by people in the line behind me” and “time is short - lots of rushing, distraction”. Poor access to toilets is a key issue, during journey and at destinations “no seats, everyone stood and had a long wait - no toilet”.

Operator staff have an important role in helping to alleviate some of these issues, however a common comment can be “some conductors are so grumpy”...“the driver can make or break my day”... “Imagine if everyone smiled”. “The main barriers are often other people thinking you can’t, instead of help you to find other ways to remain independent”

Even reaching public transport might include challenges such as “cracked pavements and potholes” or a need for “more time to cross the street” at pedestrian crossings.

4.2. People feel anxious or unsafe

People talk a lot about anxiety, about falling or injury, worried that “Drivers pull away before folk sit down”, or not feeling “confident that they could stay seated until the bus actually stops”. Train travellers and people walking through airport security report that “Being separated from luggage ... causes anxiety”. A carer notes that a “blue badge doesn’t fix problem of dropping off - dropping off then needing to drive a long way to park causes anxiety”. People have told us about empty platforms or unmanned stations with nobody to ask for help and making connections can be a source of anxiety “Live bus info not always live - have I missed the bus?”
4.3. Travel processes can be complex, inconsistent and confusing

People affected by dementia describe poor or inconsistent processes, information and environments: “signage on bus stop ... numbering can be confusing” “Buttons I have to press for doors and toilets on trains are inconsistent and confusing” “some timetables use 12 hour clock and some 24 hour clock - confusing” “too many ID/assistance cards - confusing - please combine”.

There have often been discussions about “Inconsistency about when/where we can use blue badge” ... “systems seem to differ from place to place - confusing”.

Even the design of pedestrian crossings can cause confusion. “It would be better if you could see the green man when crossing” or “the green man isn't always on the opposite side of the road”.

People are calling for simplicity and consistency- “A message for Transport Scotland ... Is it better to use National Concessionary Card or Senior Railcard? Make it Simple!” and “A message for FirstBus - Consistency is very important” “A message for Bus owners ... could you look at changing the bus time table to make it more easy reading?”

4.4. The inequalities of travelling with dementia

A number of issues have been raised suggesting inequalities when travelling with dementia. The increased use of technology can enable people but can also be a barrier “I don't want to/can't buy online - disadvantaged?” ...“cheaper tickets are online - discriminatory”. Could there be “discounted services and deals for multiple journeys”? People have discussed the “rules for bus wheelchair spaces not (being) clear” . There has also been some confusion and misunderstanding around the eligibility of people affected by dementia to obtain Disabled Parking permits (Blue Badges).

4.5. A Lack of knowledge about available support

We have observed that, while people affected by dementia are a great source of peer support, local information and ideas about travelling well, there is sometimes a lack of awareness of assistance that is available. This might be explained by the complexity of some systems and eligibility. However, widely available support such as ‘Passenger Assist’ or aids such as the Thistle Card or First Group’s ‘Better Journey’ cards have been largely unknown or untried by the people affected by dementia that we have worked with.
5. Discovering insights - working with people affected by dementia

We have learned these insights by working with people affected by dementia, spending time learning about their lives and what it is like getting out and about, using travel and transport services. We have done this in three areas around Scotland, meeting with people affected by dementia along with carers and support workers, connecting through local dementia support organisations and Life Changes Trust-funded projects, joining conversations in existing safe spaces.

5.1. Gathering insights through conversation

By creating the right context and framework for conversation we can hear about the whole experience of getting out and about, from planning the journey to buying tickets, from finding a parking space to waiting at the bus stop. Everybody has a contribution to make - whether it is a present day experience or a memory of past travels. By talking about mobility rather than transport - generally getting out and about - we explore the crucial stages before and after, as well as during, a journey.

We have developed a range of tools and creative activities to encourage conversations around mobility.

5.2. Drawing journeys

We ask people to sketch their favourite ways to travel and invite them to draw a picture or map to describe their journeys. Drawing almost always brings laughter, provokes meaningful conversation and often reveals hidden artistic skills! These activities can provoke rich conversations about the good and difficult aspects of getting around. We identify local transport options, specific challenges of travelling in the area and of travelling with dementia. We have used this approach with a range of groups including those with and without a diagnosis of dementia. Most people respond well and use it to share their stories.

5.3. Picture prompts

Picture prompts often lead to more specific discussions about types of transport or other aspects of getting around. We ask what's good, what could be better and then encourage groups to ask questions.... I wonder why? or Imagine if...?

Transport can be complex and a little explanation can go a long way to enabling people to understand why things work, or happen, in a certain way. In our sessions, we also imagine how things might be different, which can bring out ideas from simple tweaks to
existing services to ideas for new ways of doing things. Sometimes we present and
discuss existing support such as travel assistance cards or prototypes of ideas that have
come from previous workshops.

All kinds of ideas and discussion points come from these activities. Why are pedestrian
crossings an inconsistent design? Why is the information on a bus stop so high up? Why
does the blue disabled badge still have a picture of a wheelchair on it? Imagine if tickets
were colour coded or if we had more time to understand questions or deal with money. Examples of insights we have gathered are shown in Figure 1.

<table>
<thead>
<tr>
<th>Figure 1. Examples of insights gathered during Upstream workshops</th>
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<tbody>
<tr>
<td>This is Good</td>
</tr>
<tr>
<td>• (the road crossing has) clear sign for pushing the button</td>
</tr>
<tr>
<td>• on buses you are ‘visible’, you have to walk past the driver - on trains you’re more anonymous</td>
</tr>
<tr>
<td>• there’s community on a bus</td>
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<tr>
<td>• a pre-paid taxi means that no money handling is involved</td>
</tr>
<tr>
<td>• the picture on the bus stop is a bus!</td>
</tr>
<tr>
<td>• park and ride is good - drive familiar route then the bus does the tricky routes into town</td>
</tr>
<tr>
<td>It would be better if...</td>
</tr>
<tr>
<td>• drivers could be given training to be made aware of people needing special care</td>
</tr>
<tr>
<td>• (it was easier) getting to public transport - fewer cracked pavements and potholes</td>
</tr>
<tr>
<td>• you had more time to cross the street</td>
</tr>
<tr>
<td>• drivers didn’t pull away before folk sit down</td>
</tr>
<tr>
<td>• people felt confident that they could stay seated until the bus actually stops</td>
</tr>
<tr>
<td>• timetables were simpler</td>
</tr>
<tr>
<td>• seat belts were easier to use</td>
</tr>
<tr>
<td>I wonder why...</td>
</tr>
<tr>
<td>• cheaper tickets are online - discriminatory!</td>
</tr>
<tr>
<td>• the systems seem to differ from place to place - confusing</td>
</tr>
<tr>
<td>• purchasing tickets is confusing - some discounts are only available when bought ahead - machines are confusing</td>
</tr>
<tr>
<td>• buses with the same number take different routes!</td>
</tr>
<tr>
<td>• platform change announcements are made JUST before train leaves</td>
</tr>
<tr>
<td>• there is inconsistency about when/where we can use blue badge</td>
</tr>
<tr>
<td>• the printing is not larger on the tickets...</td>
</tr>
<tr>
<td>• buttons I have to press for doors and toilets on trains are inconsistent and confusing</td>
</tr>
<tr>
<td>• some timetables use 12 hour clock and some 24 hour clock - confusing</td>
</tr>
<tr>
<td>Imagine if...</td>
</tr>
<tr>
<td>• there was a badge to say that a person has Alzheimer’s</td>
</tr>
<tr>
<td>• there was an recognisable logo for people with dementia to show when travelling</td>
</tr>
<tr>
<td>• we had Oyster Card equivalent in Scotland</td>
</tr>
<tr>
<td>• if the outgoing and return tickets were colour coded</td>
</tr>
<tr>
<td>• everyone smiled</td>
</tr>
<tr>
<td>• someone was there to guide people</td>
</tr>
<tr>
<td>• cards such as Thistle and concession cards were combined</td>
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</table>
This is good...
The picture of the bus is 'Bus stop'.

It would be better if...
- The print was bigger and less busy.
- Change of colour - yellow background

I wonder why...
The sign is up high.

Imagine if...
The sign is lower.
5.4. Other sources of insight

While many insights have been collected during our workshops, there are other excellent sources of evidence and anecdote. Wendy Mitchell and Tom Dunne, for example, regularly write and speak about their experiences of travelling with dementia. Wendy’s dementia diary entry (1) describes some of the issues raised above, while Tom’s video about bus journeys captures the feelings of anxiety described by our groups (2).

5.5. Outcomes for people affected by dementia

During the process of gathering the stories and insights of people affected by dementia, which play a critical role in Upstream’s work, we have observed a number of positive outcomes for those involved:

- People affected by dementia make a valuable contribution by telling their story and being involved in our work
- Valuable peer support and information sharing is often part of our conversation, enabling people to travel with more confidence or access support
- In some workshops we have sought feedback about the process. The sample size has been small but, when we have asked what people liked about the workshops some have commented:

  “The opportunity to talk about different issues and to realise that there are some solutions available”

  “The company... information sharing’

  “The relaxed, informal chat - sharing views and ideas, learning about other people’s experiences. The good thought-provoking questions”

5.6. Outcomes for our regional partners

In East Lothian we have used insights and stories to raise the importance of good mobility for people affected by dementia with the Chief Executive of Lothian’s Integrated Joint Board and supported proposals for including transport in the development of the Board’s Dementia Strategy. We are now in discussions with East Lothian Council about including people affected by dementia in transport planning.

“Transport can be a major challenge for people affected by dementia but Upstream has brought it into focus, helping us have conversations about getting around and

1 http://www.upstream.scot/blog/2017/3/1/my-thoughts-on-continuing-to-travel

2 http://www.upstream.scot/blog/2016/8/1/making-connections
making important links for local decision makers between mobility, health and wellbeing. Upstream is now recognised in East Lothian as having the potential to bring the voices of people affected by dementia into wider conversations about health, housing and local planning as well as future transport services. There is potential to take the work with Upstream further, building on the work already done. East Lothian is developing a number of key policies, including housing and dementia. Local Area Partnership Action Plans are addressing transport. We are also establishing Peer support groups which provide a collective voice for people with dementia, friends and families. Travel is always raised in conversations and further work with Upstream would enable us to support people affected by dementia to influence decision making and thinking further. The first groups are being established in Dunbar, Haddington and Musselburgh, places with significantly diverse transport issues and experiences.”

Sue Northrop, Dementia Friendly East Lothian

In Aberdeen, Upstream has facilitated a number of conversations with the Alzheimer Scotland Positive Dementia Group, leading to a recent visit to Aberdeen Airport.

“It has been really positive working with Upstream looking at transport issues for people with dementia, as travelling and transport are such a big part of their lives still. We’ve had some really interesting discussions with the Positive Dementia Group who have given us insight into issues such as driving, bus signage, orientation and confusion around travel documents (train tickets, bus passes etc) and the group really enjoyed the opportunity to share their views”

Sarah Geoghegan, Dementia Advisor, Alzheimer Scotland, Aberdeen
## Summary - Working with people with dementia

### Key messages
- Talking about mobility can be a purposeful, creative activity. There is much to discuss and insights into daily life can emerge. Everybody has something to contribute.
- We need to think about mobility in the round - not just the mechanics of transport.
- Good facilitation and creating the right space for friendly discussion is crucial.

### Challenges
- Working with people affected by dementia is subject to their health. Some interactions such as workshops and shared journeys rely upon attendance. If this isn’t possible on the day we need to ensure that everyone has an opportunity to contribute in whatever way they can.
- Talking about living with dementia, and some mobility topics such as giving up driving, can be difficult discussion topics. We need to ensure that conversations take place in safe, supportive spaces.
- We will need to find new ways to continue to gather insights - travelling to three areas on a regular basis can be time and resource intensive but developing local relationships is extremely valuable and worth the investment.

### Opportunities
- There are many different ways to collect stories and insights. Upstream can create and facilitate these in the future to continue to collect and add to our growing collection of ‘evidence’.
- The tools that we have developed are simple, inexpensive and easy to recreate. Any group can use them to facilitate conversations around mobility. Insights that emerge can be fed into the Upstream story collection.
6. Addressing barriers to mobility

We have learned from people affected by dementia that there are a range of mobility challenges. So how do we address these?

Some assistance is already available for people affected by dementia and they, themselves, are often good sources of information about this, willing to share their own knowledge, experience and peer support. Conversations focussed on mobility can play an important part in enabling people to travel well and has encouraged us to continue to work with groups and develop plans to empower others to facilitate conversations about mobility in the future.

We have also learned that many of the issues that people affected by dementia have described are due to a lack of staff understanding and awareness of their needs and of the challenges of dementia. We have therefore developed training for service providers that explores those challenges in the specific context of travel and transport and this is described in Section 8.

Many of the challenges that people face are due to inconsistent and confusing systems, services and products. In order to be more enabling, service providers need to consider redesigning information provision and environments as well as products such as tickets. We have therefore designed a programme of training that builds on a better understanding of dementia through to support for service design and innovation. This process is described in Section 9.

Before that, however, we used the insights to create a central focus for our training - a tool that allows us to take the many and varied challenges of people affected by dementia and ask service providers - what can be done? This is described in the following section.
7. Turning insights into Upstream’s Lens - a training tool

We describe the written and verbal feedback and conversation points during our workshops as *insights*. However, blog posts, newspaper articles, radio interviews or chance encounters can also reveal useful information about travel challenges or the ways in which people overcome them. Insights that we have gathered to date are just the beginning. This collection can grow over time if we put tools in place to allow people to tell their stories and for Upstream to collect and share them. This will form part of our proposal for further development.

We have listened to stories, analysed and grouped insights into broader descriptions of challenges that people affected by dementia can face and described this as the *Upstream Lens*.

Rather than simply providing mobility service providers with individual examples of things that could be ‘fixed’ we also want to provide a more comprehensive ‘Lens’ through which they can view and assess their processes, procedures and services. Not only does the Lens show the key areas of concern for people affected by dementia along with specific examples, it can also show a growing collection of solutions and opportunities - examples of where people are already working towards, prototyping or

<table>
<thead>
<tr>
<th>Stories and insights</th>
<th>What can be done to...</th>
<th>Ideas and solutions</th>
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<tbody>
<tr>
<td>falling on buses</td>
<td>improve confidence</td>
<td>existing solutions</td>
</tr>
<tr>
<td>lack of experience</td>
<td>reduce anxiety</td>
<td>ideas from Upstream</td>
</tr>
<tr>
<td>complicated systems</td>
<td>ensure equality</td>
<td>ideas from people</td>
</tr>
<tr>
<td>poor signage</td>
<td>enable community</td>
<td>affected by dementia</td>
</tr>
<tr>
<td>poor information</td>
<td>build hope</td>
<td>prototypes</td>
</tr>
<tr>
<td>reliance on technology</td>
<td>ensure consistency</td>
<td></td>
</tr>
<tr>
<td>noise, discomfort</td>
<td>improve safety</td>
<td></td>
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<tr>
<td>lack of services</td>
<td></td>
<td></td>
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<tr>
<td>missed connections</td>
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<tr>
<td>lack of time</td>
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<tr>
<td>poor use of language</td>
<td></td>
<td></td>
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<tr>
<td>inconsistent information</td>
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We have listened to stories, analysed and grouped insights into broader descriptions of challenges that people affected by dementia can face and described this as the Upstream Lens.

Rather than simply providing mobility service providers with individual examples of things that could be ‘fixed’ we also want to provide a more comprehensive ‘Lens’ through which they can view and assess their processes, procedures and services. Not only does the Lens show the key areas of concern for people affected by dementia along with specific examples, it can also show a growing collection of solutions and opportunities - examples of where people are already working towards, prototyping or
implementing solutions. There are already many good ideas being developed, for example:

- a lanyard for people with hidden disabilities being trialled at Gatwick Airport
- videos of walking routes from stations to venues
- the Safe Places scheme for people feeling vulnerable when out in their community

The Upstream Lens can act as a place to collect more insights and ideas to help mobility service providers to understand how particular travel challenges can impact on people affected by dementia and how solutions might work in their domain.

We believe that the Lens offers a number of benefits:

- It provides a way to make sense of insights and examples in the future
- It provides a framework for conversations inside an organisation and also with people affected by dementia - everyone can make a contribution
- It moves away from a ‘tick-box’ approach to making services more enabling for people affected by dementia, taking the emphasis away from individual ‘fixes’ and asking us to consider a more holistic, people-centred approach to providing a service

Crucially, we believe it can form the basis of an ongoing, sustained conversation about how enabling a service is - a framework to develop an inclusive design approach. While technologies, products and franchise winners will inevitably change, the Lens encourages us to continue to consider these aspects of a service. What are we doing to ensure consistency? The question is independent of the current technology in place or which service provider currently holds the franchise for serving a particular route. It is also a question that can be continually asked, considered and addressed.
8. Developing training for mobility service providers

Having collected a range of stories, insights and experiences of people travelling with dementia, we have used them to develop four Upstream training formats. We have trialled each of them, working with four major transport operators and service providers in Scotland - First Group, Stornaway Airport, Aberdeen Airport and Virgin Trains East Coast:

8.1. Conversations with people affected by dementia

To date we have arranged for a service provider to join us in two of our group conversations with people affected by dementia. In both cases the staff commented on the value of being part of the discussion. This is described in our blog post Being There, after a representative from First Aberdeen had joined us for a workshop.

‘He reflected afterwards that sometimes the small things can make the biggest difference. He also wondered about who he could bring back with him next time - it’s important for other colleagues to be part of the conversation. Of course, he could take the notes and questions back with him, but to really get a sense of what’s important, you had to be there’.

An important lesson from these interactions was that this is a two-way conversation. Whilst Mobility Service Providers have much to learn about the challenges of travelling with dementia, we all have much to learn about the complexities of providing mobility services if we are work together to build more enabling transport.

Designing further opportunities for conversations between people affected by dementia and mobility service providers will build a shared understanding of everyone’s challenges and this will feature in our proposal for further development.

8.2. Introductory workshops for service providers

Introductory workshops have been used in a number of settings where a mobility service provider wants to explore how Upstream can help them. To date we have delivered these workshops at Aberdeen Airport, Stornoway Airport (part of Highlands and Islands Airports) and to Virgin Trains East Coast customer advisors. Each session has consisted of:

3 Being There, Upstream blog www.upstream.scot/blog/2016/5/12/being-there
an introductory exercise and discussion about our travel stories and challenges
an overview of Upstream’s work - the importance of considering travelling well with dementia, sharing insights and stories from people affected by dementia
a description and exploration of the Upstream Lens
an exploration of how this work fits with the organisation’s needs/requirements
discussing ideas for how we might work together

This session takes between one hour and ninety minutes to deliver.

**Stornoway Airport**
Our travels to the Western Isles have taken us through Stornoway airport a number of times. It is a small transport hub, compared to the larger international airports and yet it is a vital part of island travel. After an initial meeting with five airport staff (including fire, security, customer service staff) they asked to learn more about dementia. We worked with the local An Lanntair project and Alzheimer Scotland to deliver a workshop that incorporated a Dementia Friends session, followed by a discussion about the work environment and services provided at the airport, based on a better knowledge of dementia.

The workshop was well attended with around 12 airport staff including fire, security, Loganair, the airport manager and a representative from the Patient Transport department at the Western Isles Health Board in Stornoway. This was an important link as patients travelling to appointments on the mainland often fly from the airport and the health board make the travel arrangements on their behalf. Good information about passenger assistance needs is vital and the various parties involved in organising patient travel need to be aware of the challenges of travelling with dementia.

The outcome from the workshop was increased awareness of dementia, some learning from Upstream work highlighting the challenges of travelling with dementia and the beginning of an exploration of the airport services from the point of view of a people affected by dementia. Next steps are likely to include a workshop at the airport with people affected by dementia, exploring the environment and services with them.

**Aberdeen Airport**
An approach to Aberdeen Airport was met with an enthusiastic response to learn more about travelling with dementia. The Terminal manager coordinated around 25 airport staff for an Upstream introductory workshop including retail, security, passenger assist, safety, management, taxi drivers and others. Upstream contacts from Alzheimer Scotland, ACVO and ESP also attended.

The workshop consisted of an introduction to Upstream methods and an invitation to explore what might be helpful next steps. Staff discussed their own travel experiences and some of the learning and insights from Upstream so far. It was well received and
generated interest in doing more. Alzheimer Scotland followed up with two Dementia Friends sessions in the following months.

“… it really helped to raise awareness of some of the key issues and generated an interest among, not just those who directly participated, but some of their colleagues as well, to understand more. This … led to the successful delivery of the Dementia Friends training programme to two groups of staff shortly after.”

Aberdeen Airport Duty Manager

“The enthusiasm from Aberdeen airport and their willingness to engage has been fantastic. Staff from various departments attended the Dementia Friends session and we are now looking forward to working with them further in making the airport more accessible by involving the Positive Dementia Group in their Disability Access Day”

Sarah Geoghegan, Dementia Advisor, Alzheimer Scotland, Aberdeen

More recently Upstream facilitated a visit to the airport for the Positive Dementia Group, exploring the environment and services with staff as part of Disabled Access Day (see section 6.5)

8.3. Focussed training sessions for service providers

In September and October 2016, we had the opportunity to work with three groups of mobility assistance staff at Waverley Station. These focussed training sessions reached ca 45 staff, were well received and provided excellent preparation for the associated Shared Journey which focussed on Waverley Station (described in 6.4). Each session consisted of:

- introduction to the importance of travelling well with dementia
- dementia awareness session - delivered in partnership with, or informed by the Age Scotland Early Stage Dementia Project. Introduction to some facts and figures and the challenges of living with dementia
- description of Upstream and the learning so far
- description and exploration of the Upstream Lens
- consideration of the services that the operator provides, using participants’ new knowledge of the challenges that dementia can bring (in this case, walking around and observing Waverley station)
- considering service improvements based on these observations, drawing from staff experience and expertise
- designing a shared experience with people affected by dementia
- consideration together of next steps - how we might work together
This format takes between three and four hours to deliver.

We have had positive feedback from people attending our workshops and, in each case, a willingness to follow up with further work.

“I found the training days offered a lot of information and the feedback I have received from the guys has been so positive that they have asked for follow up days to support what they have already learned.

I look forward to helping with further events and where I can assist.

Thank you so much for delivering the training days to our teams it has been very worthwhile and valuable.”

Service Delivery Manager, Virgin Trains East Coast

These focussed training sessions played a vital role in our model of the shared journey described below.

As a result of this activity at Waverley Station, some introductory workshops have since been held with around 25 Virgin Trains East Coast customer advisors and we hope to promote the various training formats throughout the Virgin Trains East Coast network.
8.4. Experiencing a service together - a Shared Journey

While working with people affected by dementia and service providers separately can reveal useful insights and provide opportunities for people to contribute, we believe that the most powerful learning experience - for everyone concerned - is to bring people affected by dementia together with those providing services to experience each others challenges and develop a shared understanding of potential solutions. Ideally, this means experiencing a service together.

During the early stages of the project we learned about the work of the British Transport Police in North East England who were developing ‘supported journeys’, accompanying people affected by dementia on short rail journeys to improve their confidence to travel again\(^4\). We adopted and extended this model by organising a journey for staff and people affected by dementia to take together - a shared journey - taking an opportunity to not only improve passenger confidence but also for staff to learn about travelling with dementia at first hand\(^5\).

Since the Edinburgh Festival Theatre was planning to host a dementia-friendly performance in October 2016, just after our workshops with Virgin Trains staff at Waverley Station (described above), we planned a journey that would incorporate the workshops as a preparatory phase and the performance as the journey destination. Through our connection with Dementia Friendly East Lothian we invited members of Dementia Friendly Dunbar to trial this approach with us.

We therefore coordinated a partnership approach to the journey that brought together three Life Changes Trust-funded projects, a group of people affected by dementia and a transport operator:

<table>
<thead>
<tr>
<th>Upstream</th>
<th>project lead, workshop delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Virgin Trains East Coast</td>
<td>training partner, travel provider and coordinator, staff as co-designers</td>
</tr>
<tr>
<td>Age Scotland Early Stage Dementia Project</td>
<td>workshop delivery partner (Life Changes Trust-funded)</td>
</tr>
<tr>
<td>Dunbar Carers Group</td>
<td>people affected by dementia as project partners and co-designers</td>
</tr>
<tr>
<td>Edinburgh Festival Theatre</td>
<td>performance sponsor and destination (Life Changes Trust-funded)</td>
</tr>
</tbody>
</table>

\(^4\) [Dementia Friendly Stations](http://www.upstream.scot/blog/2016/7/4/dementia-friendly-stations)

\(^5\) [Shared Journeys](http://www.upstream.scot/blog/2016/10/24/shared-journeys)
During the months leading up to the journey, we visited the Dunbar Carers Group a number of times to build relationships and to explore and design the journey with members of the group. Some felt, for example, that the day would be too long and so an alternative was designed to allow one couple to travel to Waverley, tour the station and then return directly to Dunbar. In the meantime, Waverley staff were being consulted about how best to structure the visit their during preparatory workshops.

- The group met at Dunbar Station
- We travelled with a Virgin Trains East Coast (VTEC) Manager to Waverley station, with tickets and passenger assistance kindly provided by VTEC
- The group was met at Waverley station by mobility staff who had attended preparatory workshops and hosted at the station for over an hour, touring the facilities, discussing ticketing, concessions, signage and more.
- We travelled onto the Festival Theatre by taxi
- The group had lunch at the Theatre’s newly reconfigured dementia-friendly cafe and then enjoyed the performance
- We travelled back to Waverley by taxi and back to Dunbar with a VTEC Manager, again with tickets and passenger assistance kindly provided by VTEC.

The day was a success with very positive feedback.

“…Just wanted you to know that the time I spent with the ladies and gentlemen and their carers on the day they visited the theatre was amazing. It was so lovely to learn about the people they were and the problems they face now. I found meeting the carers/friends of these people very inspiring - so much so that I have become a member of Dementia Friends Scotland and have contacted my local support group and have offered my services to any of their members who want advice/help to travel by train…”

Service Delivery Manager, Virgin Trains East Coast

We have since returned to the Dunbar group to follow up and review the experience and what the group had learned. People reported that they felt more comfortable about taking the train and had learned about services such as Passenger Assist and railcards in addition to specific support available at Dunbar and Waverley Stations.

Feedback from a member of the Dunbar Carer’s Group:

What did you like about the day?
‘Travelling in good company, meeting friendly and helpful people, learning new things.’

Do you feel you learned something about travelling by train?
'That it needn’t be a stressful experience with a person with dementia'

Will you travel again by train?
‘Yes. If my wife and I had to go to Edinburgh we would use the train in preference to the car or bus.’

Plans are in place to do a similar review with Virgin Trains East Coast staff. We worked with Hee Haw Films in Edinburgh to create a film of the experience and we are planning to use this to promote the training model to other operators as well as throughout the Virgin Trains network.

8.5. Experiencing a service together - walking the process

We have taken a similar approach at Aberdeen Airport. Approximately 25 staff attended an Upstream Introductory Workshop in August 2016, followed by Dementia Friends sessions delivered by local Alzheimer Scotland staff. In March 2017 we returned with five of the local Positive Dementia Group, where we worked with staff, walking through check-in procedures and the security process. Staff discussed and demonstrated assistance that is available and members of the Positive Dementia Group shared experiences and opinions. It was a valuable and enjoyable experience for everyone concerned and several members of the group reported feeling more confident about considering air travel again. Airport staff found it helpful to talk directly with people travelling with dementia.
# Summary - Developing training for Mobility Service Providers

## Key messages
- Upstream training has been well received - travelling with dementia is a meaningful, interesting topic to explore with staff.
- Service providers are at different points of readiness to engage - when discussions take place there is always an interest and willingness to learn more.
- Service providers have their own experience of working people with dementia they have already encountered in their service - there is a demand for more information and greater awareness about dementia.
- Bringing people affected by dementia together with people who operate mobility services is one of the most valuable outcomes from the project to date.
- When working and learning directly with service providers, people affected by dementia have reported increased confidence to travel.
- It is possible for people affected by dementia to be full and active partners in all stages of a training process - whether directly involved or indirectly through their insights and stories.

## Challenges
- Transport services are busy environments - it is difficult to secure staff time to undertake a workshop or follow up from work. We need to fit with existing training schedules.
- A willingness to consider service improvement requires an understanding of the challenges and the value of making a change. This requires time and investment by the service provider.
- Organising opportunities to bring people affected by dementia together with operator staff can take time and needs to be framed as part of a wider process, not just a one-off meeting.

## Opportunities
- We now have a training process in place and a film to promote our collaboration with Virgin Trains East Coast - we foresee opportunities to work more with them to spread the training model and shared journeys across their network.
- There is definite interest from operators to understand and implement more inclusive and creative ways to engage with customers and to train staff.
- Enabling mobility is on the agenda of transport stakeholders although there is a need to make the actions simple and actionable.
- By bringing together the many and varied players that make up a journey we can foster inclusive conversations and create joined-up solutions.
9. The Upstream training model - a framework for service improvement

A key Upstream aim is to support service providers through a process that delivers **service improvement**. This process is designed to enable people affected by dementia, where possible, to be active partners in every part of this process, contributing their insights, experiences and stories to create training experiences that make a lasting impact.

The figure below describes the Upstream model of training. It is applicable to all service providers - those related to transport and beyond.

1. It begins with preparatory engagement and workshops with service provider staff, learning about travelling with dementia, informed by our conversations with people affected by dementia.
2. Staff observe their services through the Upstream Lens, walking around travel environments, considering how enabling their service might be for a people affected by dementia.

3. Staff reflect on their observations together and their and own understanding of the impact of dementia in the context of their own service. They consider their own ideas for how services might be improved.

4. Upstream brings mobility service provider staff and people affected by dementia together for a shared experience - for example, a journey, a tour of a station or a walk through of an airport check-in process. This can reveal new challenges or reinforce issues discussed theoretically in the workshops, through first-hand experience.

5. The next key step is to review what happened, what was learned and consider how changes could be made and how people affected by dementia could be involved in making change happen.

6. Upstream can help service providers to make a case for change, considering the business case as well as the rights of people affected by dementia and the operator’s responsibilities.

7. Implementing change and developing service improvements will take longer. This will take a service provider’s time and resource that is beyond ‘training’ and we are developing a support process that will help them through this to show real change and impact.

8. The ultimate goal is to foster continued involvement of people affected by dementia leading to a process of sustained, inclusive design and meaningful consultation.

In each step of the process, people affected by dementia can be actively involved, either through contributing their stories and insights or by being present during a training experience.

The various Upstream training formats work together to form an ongoing process that takes staff beyond awareness to understanding the impact of dementia in the context of their own service and ultimately to service improvement. Although insights from our workshops may identify some ‘quick wins’ to enable people affected by dementia to travel well, we aim to create a sustainable, inclusive process that ensure that the needs of people affected by dementia are considered in the longer term for service design and delivery beyond the initial engagement.
As described, we are working with a number of service providers to date, three of which are part way along this process.

- Staff at Stornoway Airport have had an introductory workshop and are considering a more focussed training session or shared experience.
- Staff at Aberdeen Airport who were present at an Upstream introductory workshop have worked with a group of people affected by dementia at the airport terminal, walking them through check-in and security processes and discussing passenger assistance.
- Virgin Trains East Coast staff at Waverley station have taken part in a shared experience and plans are in place to review next steps with them.

We are yet to trial the steps that are required for a longer term commitment to service improvement and the continued involvement of people affected by dementia.

![Diagram of service improvement process]

We have engaged with a number of service providers and aim to introduce them to this process. Through an existing connection with the Alzheimer Scotland Aberdeen resource centre, First Aberdeen staff have attended some of our workshops. First’s commercial director attended our workshop at Aberdeen airport in late summer. We are in discussions about how to work further with First Group. We have also had discussions with CalMac Ferries, Uber Scotland and the Community Transport Association.
10. Dissemination

In less than a year, Upstream has attracted interest across the transport, health and other sectors. By providing a focus on travelling well with dementia, Upstream provides new opportunities to talk about the importance of travelling well with dementia.

10.1. Upstream’s first conference - Travelling Well with Dementia

In December 2016 Upstream hosted a conference at Edinburgh’s Festival Theatre bringing together 70 people from around the UK including speakers from Network Rail, Transport Scotland, Gatwick Airport, Visit Scotland and various Life Changes Trust projects.

Organisations represented included Alzheimer Scotland, Caledonian MacBrayne, East Lothian Council, West Yorkshire Combined Authority, Innovations in Dementia, DEEP and many others.

We were delighted to welcome Tommy Dunne from the DEEP network and James McKillop from the Scottish Dementia Working Group who both spoke about their own experiences of travelling with dementia.

Upstream facilitated a unique gathering of people to talk about this important topic. The challenge for this event was enabling people with dementia to attend. While two of our speakers are affected by dementia, we found it difficult to attract people affected by

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6 Travelling well with dementia http://www.upstream.scot/blog/2016/12/12/travelling-well-with-dementia
dementia to attend as delegates, particularly from two of our project sites that are quite a distance from the venue, despite offering support to do so.

There were two key outcomes from the event. Firstly, we moved the conversation on from supporting people to travel on different transport modes (travelling by train, bus or plane) to supporting life events that involve transport (buying a ticket, going on holiday, attending an appointment…). It is important to consider the reason that people travel so that we attend to the many and varied barriers that might hinder them and also include the numerous stakeholders that play a role in making a journey happen. Secondly, an overarching theme in discussions appeared to be the need for the many service providers to work together to identify and reduce barriers to travel.

In the future, with further support, we want to ensure that Upstream can play a central role in this by bringing people together and creating collaborative spaces to develop solutions. Details of the event and examples of feedback comments from the event are listed in Appendix 1.

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7 Travelling well…but how? http://www.upstream.scot/blog/2016/12/19/travelling-well-but-how
10.2. Awareness-raising and influence - locally, nationally and internationally

We continue to have high-profile opportunities to highlight the importance of travelling well with dementia:

- Attracting almost 2000 visits to date from an audience of around 1000 to our website
- Made over 150 friends on Twitter, reaching a wide, international audience
- Provided statements outlining the importance of better mobility for the forthcoming Scottish Government dementia strategy and transport review
- In July 2016, the ESP Group organised a gathering of MPs and transport business leaders at the Houses of Parliament, Westminster to discuss Planning for the future of transport. Upstream was presented to this group.
- Raised the importance of good mobility for people affected by dementia with the Chief Executive of Lothian's Integrated Joint Board and supported proposals for including transport in the development of the Board's Dementia Strategy - through the North Berwick Coastal Area Partnership's Health and Wellbeing Network.
- Used Upstream methods to facilitate the local ‘On the Move’ group, which enabled the Older People’s Network to define local mobility priorities
- Published an article in Access by Design - Journal of the Centre for Accessible Environments (CAE)
- Invited to submit an article to the journal Cities and Health
- Delivered a seminar for Edinburgh Napier University’s Ageing Research Network
- Presented Upstream’s work at a number of academic conferences in the UK. In October 2016, we spoke at the Open Space Conference ‘Habitats for Happy and Healthy Ageing’ in Edinburgh which reached an international audience exploring themes such as ‘co-designing the built environment with mobility in mind’ and ‘Experiencing mobility’.
- Later in October we spoke at the Community Transport Association Scotland Annual Conference in Edinburgh. In November 2016 we presented a poster at the UK Dementia Congress in Brighton, reaching an international audience of over 700 delegates.
- Upstream will be presenting a poster at the Alzheimer’s Disease International conference in Kyoto, Japan in April 2017
Upstream will be presenting at The Scottish Transport Applications & Research (STAR) Conference, a leading annual event disseminating and debating innovation in Scottish Transport (May 2017).

In May 2017, Upstream will be leading a workshop on travelling well with dementia at the Grampian Dementia Conference.

Upstream has been invited to lead a workshop at the Promoting Inclusion, Transforming Lives International Conference in Dundee in June 2017.

10.3. Scotland’s Accessible Travel Framework

Early in the project we met with Transport Scotland, who were finalising their Accessible Travel Framework Going Further. The framework was developed with people affected by a range of disabilities and puts the importance of accessible travel into a policy context underpinned by Article 19 of the UN Convention on the Rights of Persons with Disabilities, the right to live independently and be included in the community.

Upstream is cited in the framework as an ‘especially exciting’ approach to gathering people’s experiences and views and collaborating to develop solutions. It is the only example in the document relating to people affected by dementia.

11. Future Opportunities

11.1. Dementia and driving

Driving and the process of giving up driving are issues that are often discussed when working with people affected by dementia. We have several ideas in this area that Upstream could explore and develop in its next phase.

We have had initial discussions with the Scottish Driving Assessment centre at Astley Ainsley Hospital, Edinburgh about potentially working together. This is the only centre in Scotland where drivers with a diagnosis of dementia may be assessed in order to extend their licence. While the driving assessment is a statutory process, we believe there is an opportunity to redesign the process of support for people affected by dementia and their families, all of whom are affected by the difficult transition of having to stop driving.

Upstream is in a unique position to gather the parties involved to co-create an improved support process and set of resources, developed and possibly delivered by people affected by dementia.

While our focus is on Scotland, there are Assessment Centres across the UK. We are not aware of support being offered through the process elsewhere and so the results of such a project could have an impact beyond Scotland.

This will be discussed more in our proposal document.

11.2. Developing a rights-based approach to mobility

We are working with Innovations in Dementia to explore the concept of a rights-based approach to mobility. This could be a powerful addition to the Upstream offering to mobility service providers - helping them to make a case for developing better mobility services, underpinned by a person’s rights as well as through a better understanding of dementia.

Upstream is participating in an exploratory workshop for people affected by dementia, helping them to place travel challenges into a rights framework. It is hoped that, in its next phase, Upstream, could jointly develop a resource for mobility service providers that describes a rights approach to travel and transport. This could help providers to understand the rights that people have to access and participate in their community and their role in enabling them to do so.
11.3. Community Transport

Community transport plays a major, sometimes less recognised, role in keeping people affected by dementia connected and active. Upstream has developed a good relationship with the Community Transport Association Scotland and we spoke at its annual conference in October 2016.

In addition to drawing from the experience of community transport operators, there is also an opportunity to use its network in the future to share knowledge of providing enabling services. For example, how do we develop a specification for a dementia-friendly minibus? Which operators have done this already and how do their specifications compare? How can we share this experiences with others looking to develop new services?

11.4. Designing the destination into mobility services

People travel for a reason. The destination of our Shared Journey was a dementia-friendly performance at Edinburgh’s Festival Theatre. Through this we have begun exploring the potential for involving theatres, arts organisations and other destinations, including hospitals, in working with mobility service providers to reduce barriers to attendance at appointments, performances and leisure visits.

11.5. Designing for Dementia

Having made links with Edinburgh Centre for Research on the Experience of Dementia (ECRED) and other related partners at the University of Edinburgh, Upstream has been invited to contribute to a project looking at co-production techniques that can help people affected by dementia to influence the design of wayfinding and the built environment.
<table>
<thead>
<tr>
<th>Summary - Dissemination and future opportunities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key messages</strong></td>
</tr>
<tr>
<td>🔄 Upstream is unique in its focus on travelling well with dementia - this attracts interest from a range of organisations nationally and internationally.</td>
</tr>
<tr>
<td>🔄 There are a number of projects for which Upstream can act as a research/delivery partner - some initiated by Upstream, some initiated by others.</td>
</tr>
<tr>
<td><strong>Challenges</strong></td>
</tr>
<tr>
<td>🔄 As a project we don’t currently have the capacity to get involved or explore all opportunities fully.</td>
</tr>
<tr>
<td><strong>Opportunities</strong></td>
</tr>
<tr>
<td>🔄 Improving travelling with dementia appears to be a timely focus and we need to find a way to increase capacity to explore all possible opportunities.</td>
</tr>
<tr>
<td>🔄 We are identifying a wide range of ‘unusual suspects’ that have a role to play in making mobility work - these are potential partners/clients in the future.</td>
</tr>
<tr>
<td>🔄 In addition to its own work, developing and delivering training, Upstream can be a partner in other work, delivering real change that aligns with policies such as the Scottish Government’s Dementia Strategy and Accessible Travel Framework.</td>
</tr>
</tbody>
</table>
12. Evaluation

Upstream was originally launched to develop training for mobility service providers based on the insights learned from people affected by dementia. We have achieved many of the original aims and these are mapped against our outputs to date:

<table>
<thead>
<tr>
<th>Key Aims in original Proposal</th>
<th>Outputs in original proposal</th>
<th>Upstream Activities and achievements in year one</th>
</tr>
</thead>
</table>
| Create a continuous catalogue of **ideas and insights** for mobility service design and redesign that are truly based on life experience | • Mobility-focussed workshops with people affected by dementia in 3 regions of Scotland  
• A community of people affected by dementia empowered to contribute to, co-design and co-deliver training  
• Insights into local mobility challenges, concepts and ideas for service redesign  
• A ‘how to’ guide to creating a local Upstream group | • worked with groups of people affected by dementia in East Lothian, Aberdeen and the Western Isles and:  
• developed and shared a **methodology** for talking about mobility  
• collected and shared resulting insights through the **Upstream Lens**  
• raised **awareness** of traveling well with dementia by bringing staff **together with** people affected by dementia in shared training experiences |

| Increased industry **awareness**, actions, innovation and capacity building based on lived experience of travelling with dementia | • An appreciation of the hopes and challenges of the mobility industry  
• Dementia and Mobility summit that brings together Upstream groups, Life Changes Trust projects, mobility industry leaders and others | • worked with four major **service providers**  
• held the first national **conference** on travelling with dementia  
• created a **film** with Virgin Trains East Coast  
• presented at national and international **conferences** |
<table>
<thead>
<tr>
<th>Key Aims in original Proposal</th>
<th>Outputs in original proposal</th>
<th>Upstream Activities and achievements in year one</th>
</tr>
</thead>
</table>
| Accredited training that is based on first-hand experience of travelling with dementia | • A clear pathway for the industry to deliver people-centred, dementia-aware mobility  
• New standards for customer service and service  
• Training which is co-designed with people affected by dementia and tested with JourneyCall staff | • used the insights from people affected by dementia to develop a suite of training options tested with mobility service providers  
• shared experiences that involve staff and people affected by dementia to learn together  
• developed a Service Improvement framework - a clear pathway of training that can lead to more dementia-aware mobility services |
| A sustainable, stand-alone organisation providing training and dementia-awareness resources | • funded by the services it provides.  
• A dementia-friendly mobility challenge fund which supports the development of new | This is a longer term aim that will be addressed in our proposal for Upstream phase 2 |

We originally proposed developing a guide to creating a local Upstream group. We have instead worked with existing groups who have a wide range of interests, not just mobility, and developed and shared tools that we use for talking about mobility.

Our original plan was to ‘test’ our training formats with JourneyCall Staff but in fact transport operators have themselves been willing to allow us to trial the training directly with their staff.
13. Conclusions

Upstream has delivered beyond its original aims during its first phase. We have developed and shared a methodology for engaging with people, using creative methods to encourage conversations about mobility and capture insights that emerge.

This experience indicated that:

- exploring mobility through conversation and activity is constructive and meaningful. Everyone has a contribution to make and we have witnessed valuable peer support and shared learning, swapping ideas and tips for keeping mobile. This has encouraged us to continue to work with groups and develop plans to empower others to facilitate conversations about mobility.

- many of the issues that people affected by dementia have described are due to a lack of staff understanding and awareness of their needs and of the challenges of dementia. We have therefore developed training for service providers that explores those challenges in the specific context of travel and transport.

- other challenges that people face are due to inconsistent and confusing systems, services and products. In order to be more enabling, service providers need to consider redesigning information provision and environments as well as products such as tickets.

In response to this, we have developed the Upstream Lens, a tool that translates individual travel experiences into broad challenges that people affected by dementia can face. We have successfully trialled four different training formats with four different mobility service providers. This training forms part of a wider Service Improvement Framework which gives service providers a clear pathway to take staff beyond dementia awareness to understanding its impact in the context of their own service and ultimately to service improvement. Our Framework is designed to enable people affected by dementia to be active partners in any part of this process. This framework and vision is applicable to all service providers - those related to transport and beyond.

Bringing people affected by dementia together with people who operate mobility services is one of the most valuable outcomes from the project to date. During these shared experiences, people affected by dementia have contributed their stories and concerns, helping service provider staff to gain a deeper understanding of the challenges of travelling with dementia. These experiences have equally provided a chance for people affected by dementia to learn about assistance that is available. One of the key learning points has been the lack of awareness of help that is available.

During the two shared experiences to date, people affected by dementia have expressed improved confidence to travel by train and air again.
The service providers that we have worked with have found the training to be valuable and reported interest and a willingness to explore the process of service improvement through training with us. The nature of the transport sector - shift patterns, a mobile workforce, a pressured environment - can bring challenges. Training time is often short but learning about hidden disabilities is currently a high priority and Upstream is in a strong position to provide a new service to fulfil this.

In developing this training, Upstream has attracted interest from Government, academia and industry. There is great potential for Upstream to work on a range of activities as shown by the range of projects that we have either participated in or have the potential to contribute to. However, having been operational for just one year, we have not had the capacity or time to fully explore and take advantage of all opportunities.

Upstream is beginning to occupy a unique space - an organisation that works with people affected by dementia to develop education and training based on lived experience and helps its clients to use the learning to ultimately create improved services that are more enabling for people travelling with dementia.

We are therefore developing plans for the next phase of Upstream that will aim to establish it as a training and service improvement partner, consolidating its existing work with service providers and developing opportunities with new clients.

Upstream can enable this change to happen and we will explore this in detail in a separate proposal document.
Appendix 1 - Travelling well with dementia - Upstream’s conference

Programme

Welcome and Introductions
Andrea Coburn, Life Changes Trust
Steve Cassidy, Managing Director, Viaqqio (ESP Group)

Travelling with dementia
Tommy Dunne, Chair of Service Users Reference Forum (SURF) Liverpool

Upstream
Andy Hyde, Project Lead

Upstream across Scotland
Paula Brown, Arora Dementia Friendly Community, An Lanntair, Stornoway
Sarah Geoghegan, Dementia Advisor, Aberdeen City Services
Lee Glen, Dementia Friendly Dunbar

Driving and dementia
Dr James McKillop

Travelling through airports
Ruth Rabet, Samantha Berry OCS Group UK Limited, Gatwick Airport

Spaces and Places for Everyone: Network Rail’s Inclusive Design Strategy
Margaret Hickish, Access and Inclusion Manager, Network Rail

Going Further: Scotland’s Accessible Travel Framework
Jill Mulholland, Transport Scotland

Accessible tourism
Chris McCoy, Equality Diversity Manager and Head of the Accessible Tourism Programme, VisitScotland

The future of mobility services
Terry Dunn CEO, ESP Group

What next?
A plenary discussion
Feedback from Upstream’s conference

“The most important thing I’ll take away from today is…”

- There is a lot of good will and support out there—issue is people knowing about it and accessing it.
- Hope! By working together we can improve transport so it works for everyone.
- Overview of issues—very helpful.
- Remembering that getting the right people together is more important than generating ideas. The right people = those that can make a difference + those with the problem + those who can imagine better futures.
- That there is a commitment from transport providers to make changes.
- There is so much passion to get it right! Where there is a will there is a way.
- The need to be aware of how information is made available about transport and the difficulties around using transport.
- A better understanding of dementia.
- People CAN work together to put ideas into action.
- To hear real life personal stories and feedback from speakers.
- Accessible travel as a concept really made me think about the outcomes and impact on individual lives.
- The importance of dementia awareness amongst user facing employees of transport companies.
- The importance that transport plays as a role in the lives (of people living with dementia).
- How much I take for granted when I travel. Organising A to B for me is enjoyable. Transport should be inclusive. Change may come, but progressively.
- Awareness is most important to achieve a dementia friendly community.
- The impact which people within transport operators/providers/decision makers can make to creating better transport experiences for people with dementia by listening to them and their needs.
- Need to have people with dementia involved in decisions about transport services.
- The difficulties that people with dementia face right from the start of the travel process.
- more in-depth insight into integrating the needs of people with dementia into transport…
- Resources to tap into when gathering transport information from people living with dementia in my area.

“Something I’ll do after today…”

- Be more aware of difficulties facing people with dementia.
- Think more broadly about what can be done on transport for people with dementia.
• Explain how Age Scotland can make it easier for people with early onset to get concession travel cards.
• Re-double my focus on supporting airports to become more dementia friendly.
• Mapping services in Aberdeenshire and scoping views of people with dementia in a more formal way.
• Tell people to stop complaining about “how long is this person taking in front of me.” To be patient.
• To be more cautious of how I (we) handle/look at people with disabilities.
• Be more observant of how transport can be improved.
• Consider dementia friendly training for my organisation.
• Focus on getting the right people together before I kick off future projects.
• Use this better knowledge in my work.
• Try and be more aware of invisible disabilities.
• Speak with operators, local groups and NHS/social work on making an East Lothian Strategy.
• Put all I’ve learned today into practise and share the knowledge.
• Be aware of issues people face throughout a journey from leaving the house to reaching the destination.
• Find out the most and best conditions for persons to travel, from transport to information accessibility—start to finish.
• Consider and consult PWD on every aspect of accessing community as transport is key to most experiences.
• follow up and look at airport/air travel guidance.
• Take photos of local transport to use in interviews in focus groups.

Any other thoughts? (Other initiatives we should know about? Who else should be part of this conversation?)

• Transport is a public service that must work for everyone.
• Transport provider all modes. Health commissioners. Business—large and small.
• Government, NHS, local health partnership, local community groups, transport providers and transport network planners.
• Community transport voluntary sector agencies and organisations.
• Transport user groups could be included and encouraged to include people with dementia.
• Travel needs of people with dementia needs to have a higher profile.
• To get involved in a supported travel on our networks, CalMac ferries—get our passengers involved!!
• Perhaps more representation from local authorities.
• It would have been good to hear from Transport operators - reactions to what they have heard. But recognise that’s maybe next stage? however, concrete action now needed. Keep going! Thank you!
• Supporting people during dementia friendly community work to use similar resources in transport conversations and ask them to feed back.
• Who is going to bring ‘the right people’ together - when? where? + who?