TRANSFORMING DEMENTIA CARE WITH THE GOLDEN TICKET: QUALITATIVE SERVICE EVALUATION

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FOREWORD

It is with great pleasure that I introduce this service evaluation of the Golden Ticket pilot project, hosted by my Practice – Buxted Medical Centre.

As Chair of High Weald Lewes Havens Clinical Commissioning Group (CCG) and as a GP, I endorse the Golden Ticket as a model of best practice of care and support for people living with dementia and their family carers.

We as a CCG are committed to improving the care that our patients receive at all points in their life and we will be laying out our ambitions for rolling out this model of care, in a business case to follow this report, based on the learning from this stakeholder focussed service evaluation and other evidence available to us.

This project was developed alongside our GPs who were key to ensuring it is a workable model for general practice and I’m encouraged to read in this evaluation, which patients, carers and other agencies reported favourably as to the benefits of participating.

Most importantly, I’m delighted that initial findings demonstrate an improvement in peoples’ quality of life and wellbeing, living with and affected by dementia in a way that we had always anticipated and hoped for, by this new way of working.

I would like to pay particular thanks to my colleagues involved in the delivery of the project, and to all of the patients and carers who made this work happen.

Dr Elizabeth Gill

Chair, High Weald Lewes Havens CCG
ACKNOWLEDGEMENTS

This report would not have been possible without the support and kindness of everyone who participated in its construction. I was astounded at how far people were willing to contribute to the project and I witnessed people putting their heart and soul into making this extraordinary work happen.

A big thank you to all of the patients and carers who agreed to be interviewed and appreciation is also expressed to them for inviting me into their homes to be able to interview them, I am extremely privileged.

To Jo Evans – thank you for all of the useful insights and for allowing me the use of the wonderful photographs that you took.

Particular thanks to Dr Emma Costello for your guiding influence in the formation of this work and all of the staff at Buxted Medical Centre for your patience during interviews at the Practice.

I am grateful to have been asked to carry out this service evaluation on behalf of High Weald Lewes Havens Clinical Commissioning Group (CCG). With special thanks to Kim Grosvenor for making the Golden Ticket happen.

Finally, to Makeisha Birdine who tirelessly assisted in the coordination of this service evaluation – a massive thanks.

Dr Adam Gill
EXECUTIVE SUMMARY

The Golden Ticket was a pilot project that aimed to transform the lives of patients and carers living with dementia by delivering more holistic care closer to home. The service was geographically based around Buxted Medical Practice and involved several constituent parts of both medical and wellbeing interventions. The model included provision of Primary and Community care, a Secondary Care service, a package of wellbeing interventions and a ‘Golden Ticket Guide’ role.

A qualitative service evaluation was undertaken to find out whether the Golden Ticket had improved the quality of life for those living with dementia. The aim was to capture the patient and carer story, including their experience within the pilot and to understand how the service had begun to impact on their lives. The evaluation employed a three-part investigation method utilising interviews, observations and surveys to understand how patients, carers and staff demonstrated or reported improvements in their wellbeing and/or healthcare services.

This approach was taken in order to go beyond what is usually deemed as engagement within the NHS and gain insight into the lived patient and carer experience. Insights were tested at several stages of the service evaluation. Investigations were semi-structured and observational in nature. Insights were captured to inform future service delivery across the wider High Weald Lewes Havens Clinical Commissioning Group (CCG) locality and to ensure its sustainability.

A key benefit of the Golden Ticket pilot was the community that began to develop around the participants and its interventions. This community became a profoundly important part of the day-to-day lives of those living with dementia. It became a support network for both patients and their carers, both whom had often previously felt socially isolated and reported a poor patient experience. Some of these heart-warming stories are captured as case studies and serve to demonstrate the human impact of the service.

The findings presented in this report demonstrate the positive impact that the pilot had on patients and carers. Indeed, most people reported an improvement in their sense of wellbeing and confidence to self-manage. Specifically, there was evidence to suggest that:

1. **Quality of life** for patients living with dementia improved
2. People involved felt able to **live more independently**
3. There was a reported improvement in access to **information and advice**
4. **Wellbeing interventions** were hugely beneficial to patients and carers
5. **Mental health and wellbeing** improved for patients involved
6. **Carers’ experience** and reported outcomes improved
7. Golden Ticket workforce believed it offered an improved **patient experience**.

The findings of this report represent a success for patient-centred models of care and provide the evidence in support of further roll-out. Insight into the lived experience of patients and carers has real implications for health and social care commissioners looking to transform dementia services for their populations. Findings can inform deployments in other areas and success factors should be noted, one being the sheer support and dedication...
from the local community, third sector organisations, Primary and Secondary Care, working together to deliver the model.
The Golden Ticket was a pilot project commissioned by High Weald Lewes Havens Clinical Commissioning Group (HWLH CCG) to transform care for patients and family carers living with a dementia. The pilot involved establishing a multi-agency service, designed to deliver a relationship-based approach to caring and supporting those living with a dementia with a particular focus on community-based wellbeing interventions to enhance independence and quality of life. The pilot ran for a period of 3 months and reached out to a total of 40 patients and their carers.

The pilot included a sample of the population of those registered with a diagnosis of a dementia at Buxted Medical Centre in the HWLH CCG locality, a semi-rural area of East Sussex. As a key feature of the pilot was to evaluate the impact on peoples’ independence and quality of life (including family carers,) a cohort of patients was selected from a list of diagnosed patients, who were living in their own home and by definition, would in all likelihood, be living with a family carer in the majority of cases. A clinical review of dementia services prior to the Golden Ticket, highlighted delays in receiving a diagnosis from the point of raising concern with a GP, access and choice of services, poor patient outcomes and a heightened sense of carer strain, as key issues that patients and carers were experiencing.

The need for change was not only a local issue but is also a national challenge. The ‘Dementia Challenge’ outlined in NHS England’s NHS Five Year Forward View calls for a coalition of statutory services, local communities and businesses to establish ‘Dementia Friendly Communities’ - facilitated by local ‘Dementia Champions’ – to help those living with a dementia to fully participate in community life.

The philosophy of care on which the Golden Ticket project was designed, was informed by best practice, a European literature review of what works best, (Alzheimer Cooperative Valuations in Europe-ALCOVE), NICE Guidelines, the National Dementia Strategy and the work of Professor Dawn Brooker (University of Worcester, Association of Dementia Studies), which notably draws on Tom Kitwood’s non-medicalised model of person-centred care.

On this evidence and best practice, the Golden Ticket model endeavours to support patients and carers in all aspects of their life and journey with dementia. This is both from the relationship that they have with each other and their family, to the relationship that they have with their community and professionals in health and social care. In short, the ethos of the pilot was that supporting these relationships would enable patients and carers to truly ‘Live Well’ with dementia, which was the aspirational basis, for the National Dementia Strategy, (Department of Health, 2009).
THE SERVICE MODEL

The Golden Ticket service model was geographically based around Buxted Medical Centre and involved a number of partner organisations that worked together to deliver holistic care to patients and support to their carers, as close to home as possible. In the first instance, the model involved several constituent parts of both medical and wellbeing interventions, including:

1. THE GOLDEN TICKET PRIMARY CARE AND COMMUNITY INTERVENTION

Golden Ticket Review Meeting with a Primary Care Worker (Paramedic) at Buxted Medical Centre, introduction to the Golden Ticket Guide Role (provided by the charitable organisation Know Dementia,) a Pharmacy Review led by the practice-based Superintendent Pharmacist with Guide present during the meetings and running consecutively a Peer Support Café, run in the local Pub.

In addition to the Primary Care Review Meeting, there was a weekly ‘BLIP’ Clinic¹ for when family circumstances were changing and needed a timely response. This was staffed by the Paramedic with support from a GP and Secondary Care Clinical Nurse Specialist (SPFT) with access to a daily telephone line (available 12.00-14.00) for information and advice from Secondary Care for the Primary Care workforce. Adult Social Care worked alongside the model of care to undertake assessments and to provide a timely response to crisis and respite need.

2. THE GOLDEN TICKET SECONDARY CARE SERVICE – SUSSEX PARTNERSHIP NHS FOUNDATION TRUST (SPFT)

The Memory Assessment Service (MAS) and Multi-Disciplinary Team (MDT)² were hosted by SPFT and included the following roles and functions:

- Clinical Nurse Specialist
- Community Psychiatric Nurse (CPN)
- Psychiatrist & Psychologist
- Occupational Therapist
- Comprehensive assessment and diagnosis in peoples’ own home AND management of dementia
- A crisis function Out of Hours and;
- A telephone hotline to provide support to the Primary Care workforce

¹ ‘BLIP’ is not an acronym for a service or a condition, rather a description for a change of patient circumstances preceding a potential decline if not responded to in a timely way. The BLIP clinic then, was a place for people with dementia to present and gain medical support.

² A Social Worker formed part of the MDT discussion.
3. THE GOLDEN TICKET PACKAGE OF WELLBEING INTERVENTIONS COORDINATED BY ROTHERFIELD ST MARTIN

Rotherfield St Martin supported patients and accompanying carers to access free wellbeing interventions and events as part of the Golden Ticket pilot. These were part of a range of wellbeing approaches which included physical, emotional, memory and occupational interventions.

The non-clinical activities and support for both patients and carers is a paradigm shift in how dementia patients are traditionally cared for. These interventions and the support provided by the Golden Ticket Guide (Know Dementia) role are what really make the service model transformational for patients and carers. More detail on what was offered is shown in Table 1 below.

Table 1 - Wellbeing Interventions

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<tr>
<th>Intervention</th>
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<tr>
<td>Physical Wellbeing</td>
<td>Weekly physical activity classes at Freedom Leisure Centre in Uckfield</td>
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<tr>
<td>Emotional Wellbeing</td>
<td>Popular weekly ‘Café’ at Buxted Inn Pub, which often included special events such as British Red Cross hand massage, pets as therapy, a Christmas party and wildlife A&amp;E</td>
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<tr>
<td>Emotional Wellbeing</td>
<td>Crafts and tea events held at a local residential home (Hurstwood View) near Buxted</td>
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<tr>
<td>Mental Wellbeing</td>
<td>Monthly events often involving reminiscence activities, singing and refreshments hosted at St Mary’s Hall, Buxted</td>
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<tr>
<td>Occupational Wellbeing</td>
<td>Fortnightly activities at Wilderness Woods including woodland craft workshops and outdoor cooking</td>
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4. THE GOLDEN TICKET GUIDE ROLE – KNOW DEMENTIA

As part of the pilot, a Sussex-based charity (Know Dementia) was asked to work with the CCG to support development of the Golden Ticket Handbook and to act as ‘guides’ for patients and carers by providing emotional support, advice and information, as well as practical guidance and advance care planning.

Specifically, the guide role was intended to be the first point of call when support was required. They would then coordinate access to further support and discuss requirements with participants. Some support topics included advanced care planning, the importance of socialising and activities, DVLA issues, family and carer issues and emotional wellbeing.

An overview of the service model is shown below in Figure 2. The roles of key organisations involved in delivering the Golden Ticket pilot are listed in Appendix 1.
Figure 1 - Golden Ticket Service Model
Dr Adam Gill was commissioned to conduct a qualitative service evaluation over the lifetime of the pilot project by interviewing and observing patients, carers and workforce members. This report is the sum result of all of the elements of the service evaluation and fits into a suite of evaluations, including the quantitative evaluation carried out by the Kent Surrey and Sussex Academic Health Science Network.

**PURPOSE**

The purpose of undertaking a qualitative service evaluation was to capture the patient and carer story and their experience in the pilot service as well as how it impacted on their lives. This approach was employed to be able to go beyond engagement and delve deeper to gain insight into lived patient and carer experience. Insights were tested at several stages of the service evaluation and investigations were semi-structured and observational in nature.

The aim was to find out whether the Golden Ticket had improved the quality of life for those living with a dementia by telling the story of participants involved in patient-centred care and to learn about improvements in the patient and carer experience. The aim was to also gain insights to inform roll-out of the service across the wider High Weald Lewes Havens CCG locality and its sustainability. The insights raised in this report will therefore inform future service delivery.

The service evaluation involved an investigation into the following key areas:

- Quality of life for patients living with dementia
- Ability to live independently
- Access to information and advice
- Outcomes of a range of wellbeing interventions
- Mental health and wellbeing for patients and carers
- Sustained or improved physical health
- Carer experience and outcomes as a result of participation
- Workforce perception of system improvements

**APPROACH**

The report approach was based on the definition of a service evaluation, defined by The National Research Ethics Service (NRES) as: 'Designed and conducted solely to define or judge current care' (209: 3).

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3 For more information on Adam Gill Projects services see: [www.beyond-insights.com](http://www.beyond-insights.com)

4 The results were not available at the time of publication of this report.
According to University Hospital Bristol's interpretation of the NRES guidance\(^5\), a service evaluation is used to:

Judge a service’s effectiveness or efficiency through systematic assessment of its aims, objectives, activities, outputs, outcomes and costs. (A service evaluation asks questions like): has this service been a success? How satisfied are patients with the service being provided?\(^6\)

That withstanding, the service evaluation employed a three-part investigation method utilising interviews, observations and surveys to understand how patients, carers and staff demonstrated or reported improvements in their wellbeing and improved experience of their healthcare services. Of interest was how well supported patients and carers felt as a result of participating in the project. Attention was paid to how well the project ran and lessons learned from staff involved in delivering the Golden Ticket.

The service evaluation was carried out collaboratively with patients and carers, commissioners (CCG), the Primary and Secondary Care workforce, third sector, and community activity and Guide providers.

A total of 40 patients and their carers were chosen from a full mix of patients either diagnosed, or newly diagnosed with a dementia. Patients were limited to this number mainly due to time pressures of the 12-week pilot project, yet being significant enough to demonstrate thematic outcomes. Due to a number of patients withdrawing from the Pilot, the final cohort consisted of 37 patients; 13 of which were previously only known to Primary Care, 18 from Secondary Care and 5 transferring from the existing Memory Assessment Service. One further referral was received during the course of the Pilot Programme.

Those involved in the evaluation were selected by Dr Emma Costello and were visited in their homes before the project began to ensure suitability and availability.

Informed consent was obtained by Dr Costello in people's homes and by James Gill (Paramedic leading the Primary Care Review Meetings) in consultation with patients and carers. Before conducting interviews, I also checked that people consented and ensured they understood the purpose of the interviews and provided people the opportunity to opt-out at any stage (up to the date of publication of this report). I asked participants if they consented to using their names in this report, which all did.

Associated data collected by third sector providers like Know Dementia and Rotherfield St Martin have informed the shape of this report.


\(^6\) University Hospitals Bristol NHS Foundation Trust (2015) ‘Is your study research, audit or service evaluation?’, accessed 01/10/15, available at: http://www.uhbristol.nhs.uk/research-innovation/information-for-researchers/is-your-study-research,-audit-or-service-evaluation/service-evaluation/
INTERVIEWS

Interviews were an essential avenue into the lived experiences and often intimate details of the lives of the patients and carers affected by dementia. The interviews were carried out in the homes of patients and carers, although when it was requested, these were carried out in public places. Interviews were semi-structured in order to allow for the natural flow of conversation about other, often unexpected insights to emerge. The stories that emerged and the findings that these produced are described in detail in Part Three. Due to the nature of different stages and acuity of dementia patients responded with varying ability to questions posed.

A total of 15 patients and 16 carers were interviewed between October 2015 and February 2016. Four follow-up case study interviews were held with previous participants between December 2015 and January 2016.

Twenty interviews were conducted with the Golden Ticket workforce including Primary and Secondary Care staff, commissioner(s), third sector partners and activity providers between January and February 2016. Participants were invited to be interviewed if they had worked in the project as a member of the workforce team. Interviews were conducted face to face at the CCG offices and others were carried out in people’s residences or over the telephone.

OBSERVATION

By overtly observing planned activities organised by Rotherfield St Martin, I was able to learn more about how the Golden Ticket community had grown. This was evident in the formation of relationships that continued outside the forum of the Golden Ticket activities, often extending out into the lives of participants on a day to day basis.

Indeed, by being open with all participants about my involvement in the project when interviewing people, I was identified at activities by those I had already met and often invited to participate in activities. This led to opportunities to obtain deeper personal experiential insights about people’s experience of the project.

E-SURVEYS

In order to explore and identify emerging themes regarding service delivery, an e-Survey was sent to all members of staff involved in the project. I also wanted to scope out how Healthcare Professionals (HCPs) felt about the impact of the pilot at the mid-stage point to understand what to draw out in face to face interviews. Twenty responses to the e-Survey were received in total.

7 For a list of questions asked in interviews, please refer to Appendix 2.
8 For a list of all activities observed, please see appendix 3.
NOTE TAKING

I took notes during interviews when I observed activities. When I reflected on the progress of the pilot in my own space starting on 6th October 2015 until 5th February 2016, notes were spanning some 125 pages in my notebook. Note taking covered: what I saw, interpreted, felt, observed in others, and verbatim reflection of people’s experiences.

For me, the notes taken were where I began to identify emerging themes where I was able to reflect on all of the elements of the service, the people accessing it and those providing it. The notebook then became a Birdseye view of the project and all of its workings.

LIMITATIONS

The service evaluation reflects the developments and views of the people involved. However, the review findings are limited due to the short timeframe of the pilot. Not all of the patients and carers involved had a full 12-week experience of the Golden Ticket and as such, their views are limited due to the amount of time they had experienced the service.

Out of those whom were diagnosed in their homes during the Golden Ticket pilot, only one wanted to be interviewed. The patient was extremely upset about having his driving licence revoked and didn’t want to comment beyond this upsetting experience.

Other interviewees had a richer experience and the interviews reflected broader involvement in the Golden Ticket and its offerings. With this in mind, case studies were chosen to find out more about the themes that emerged throughout the service evaluation. Much of the insight gathering draws on interviews, though not all patients were able to answer, therefore many carers answered on their behalf.
PART THREE: THE PATIENT, CARER AND STAFF EXPERIENCE

In collecting insights from patients, carers and staff, there have been a great deal of findings that demonstrate the success of the pilot. The Golden Ticket has touched the lives of many people not simply within the confines of the project, but beyond and into people’s lived experience.

The observations offered an intriguing insight into the development of the community that sprang up around the Golden Ticket pilot. The first cafe was slow and steady, with people being bought over from the Primary Care Review Meeting by either Jo from Rotherfield St Martin or Jennie from Know Dementia. Coffee and fruitcake was served by the bar staff and patients and carers talked about their experiences openly. By the end of the pilot the Buxted Inn was full to the rafters with people singing Christmas carols, eating mince pies, joking and laughing amongst themselves.

I learned about: the connections and networks that developed between people, an understanding as to why some were less active than others in the Golden Ticket, and any improvements that could be made to future service development and deployment.

Findings from interviews, observations and e-Surveys are presented below from the patient, carer and staff perspective. The insights obtained as a result of this service evaluation demonstrate impacts made on patient and carer wellbeing and experience and staff perspective on how well the project developed.

FINDINGS: THE PATIENT AND CARER EXPERIENCE

KEY FINDINGS FROM INTERVIEW DATA

I conducted semi-structured interviews with 31 people in total (patients and carers combined) and the insights obtained from these interviews are presented below.

1. PATIENT AND CARER EXPERIENCE OF DEMENTIA SERVICES BEFORE THE GOLDEN TICKET WAS POOR

In general, people appeared to be stressed when recalling their experience of services available before the Golden Ticket. In particular, people had a negative experience of diagnosis and discussing this was generally a sensitive issue.

Most people were diagnosed sometime before the pilot began, ranging from eighteen months to up to twenty years. People often told me how they received their diagnosis and this was explained to me as something which was poorly handled. Diagnosis was often through a series of different events in both Primary and Secondary Care, although diagnosis was usually done in the Memory Assessment Service.

Most people responded to the question as if it was not a good process and reported that it was often complicated and stressful due to being passed around services and needing more information than was made available. More frequently, carers would explain how this came about as patients often struggled to recall it or found it difficult to talk about.
WHAT DID PATIENTS AND CARERS SAY?

“No back up at all before (the Golden Ticket). We were sent to someone (a GP) and after diagnosis there was no follow up from the practice.”

“I was just looking after her on my own.”

“Absolutely nothing”, “none existent”, “before there wasn’t any support.”

Photograph 1: Participants at Wilderness Woods

2. THE GOLDEN TICKET WAS FAVOURED OVER THE PREVIOUS SERVICE

Even though many participants had not long participated in the Golden Ticket, both patients and carers said they preferred the service to what was previously available. Naturally, people felt uncertain about what they would experience in the early part of their involvement, but after sometime people felt like they were benefitting a great deal.

People reported that they had previously felt left out and subsequently felt more ‘looked after’. I heard people say that they felt the NHS had taken more of a direct interest in them and some couldn’t actually believe that the Clinical Commissioning Group (CCG) had asked someone to visit them in their homes and ask them how things were going for them.
WHAT DID PATIENTS AND CARERS SAY?

When asked whether people preferred the Golden Ticket to previous services people responded:

“This is the best thing that has happened to us in the last seven years.”

“Yes! Infinitely.”

“Yes, but I am not interested in the outdoors!”

“The Golden Ticket gave me my life back. I can go out and be myself. I have a totally different life (now).”

Photograph 2: Music performance at Making Memories event

3. PATIENTS AND CARERS FELT MORE SUPPORTED AND MANY BELIEVED THAT THE GOLDEN TICKET COULD HELP OTHERS

One of the strongest themes to come out of the interviews was that people felt extremely well supported as a result of participating in the Golden Ticket.

I posed the question as to whether the service had helped them or could help others. This was because some people had accessed services with differing levels of involvement and
felt that they didn’t yet need the complete service. So instead, they answered with reference to other people who might benefit from the Golden Ticket in the future.

The enormous sense of duty felt by carers in their role was also evident in all interviews. It was particularly clear that any support available was useful for them, especially as they would continue to care regardless. Most felt that they could continue in their supportive role for longer as a result of the Golden Ticket.

WHAT DID PATIENTS AND CARERS SAY?

When carers were asked whether they could continue in their caring role as a result of the Golden Ticket, some said:

“Yes (now there is) more back up available and others alongside me.”

“I suppose so but it is something I have had to do anyway.”

“I am determined to.”

One patient described the sense of pride needed to be overcome to accept support against not wanting to be seen as ‘sponging’.

“Lots of people are very private, very proud. We have had to overcome this – that is hard to swallow.”

4. RESPONDENTS FELT MORE SECURE WITH THE ‘KNOW DEMENTIA’ GUIDE ROLE

Jennie and Alex (Know Dementia Golden Ticket Guides) were clearly a formidable force within their role, acting as a guide through the Golden Ticket; visiting people in their homes and calling them to check-in on how they were doing. I noticed that people felt more secure knowing that Know Dementia were available and were particularly thankful of Jennie’s help and support. Both patients and carers responded positively about the role.

WHAT DID PATIENTS AND CARERS SAY?

“Know Dementia are far more providing, understanding and empathetic than Adult Social Care were.”

“Another point for support, I can pick up the phone and signposting is available.”

“Jennie is the one I would ring – absolutely lovely.”

“Jennie is excellent – talking and reassuring that help is there if needed.”

“Mum was sectioned and Jennie phoned the next day and was really supportive.”

“Jennie and I were dancing in the living room!”
5. SOCIALISING, ACTIVITIES AND PEER SUPPORT HAD THE BIGGEST IMPACT

Perhaps unsurprisingly given many of the findings in this report the Buxted Inn Café and socialising with other patients and carers came out as one of the strongest themes. I observed a community spring up around the café and the activities over the course of the pilot.

The community was strengthened by Jo from Rotherfield St Martin who called people regularly to remind them to come to activities and during events she would introduce people to one another. In these events it was clear to see how peer support was such a strong part of the community.

6. THE HANDBOOK WAS NOT USED BY MANY PEOPLE

Out of those interviewed, 82% of people did not use the Golden Ticket Handbook.

WHAT DID PATIENTS AND CARERS SAY?

“Not very useful.”

“Not sure who should fill it in.”

Adam Gill Projects Ltd 2016
“Jennie has filled a lot in and is useful when she is here.”
“(She) doesn't want to be reminded and the booklet is a reminder.”
“Not as much use as I thought it could be.”
“Not all parts are relevant.”
“Only useful if you can read it.”

7. INFORMATION AND ADVICE WAS EASIER TO ACCESS

Although the handbook was not widely used many people (although not all) mentioned they knew where to access useful phone numbers in the booklet. Most people appeared to know who to ask directly for more information and advice, mainly from Know Dementia or Jo from Rotherfield St Martin regarding wellbeing interventions.

However, when I asked who would patients and carers contact in times of difficulty, people often responded with uncertainty. The social worker role was mentioned by some but people did not tend to mention the Golden Ticket or BLIP clinic specifically.

WHAT DID PATIENTS AND CARERS SAY?

“Yes, I have been able to get pointed info quickly.”
“Yes, through peer support at the café.”
“Not sure, but I do know who to call.”
“I knew if I needed anything I could ring Jennie.”

8. THERE WAS A MIXED RESPONSE FROM CARERS ON WHETHER PATIENTS COULD LIVE MORE INDEPENDENTLY

The mixed response came largely because carers appeared surprised at the question, as many felt a sense of duty and had never considered not continuing in their caring role. Some carers recognised that they needed support to be able to care for their loved ones however, not everyone either wanted to answer or felt they could answer.

One patient highlighted the strength of the family unit and stated, “We don’t need help at this point; the family picks us up and drops us off.” This also suggests patients do not want to be a burden on the NHS and are keen to self-manage and remain as independent as possible.

WHAT DID CARERS SAY?

“It is helpful to leave him, come home and then pick him up.”
“I look after myself; I tend not to ask (for help) really.”
“I know it is there and available.”
“I feel absolute relief.”

“It is not sustainable but it has an alleviating effect.”

9. **ROtherfield St Martin’s Coordination Into Wellbeing Interventions Was hugely Beneficial for Participants**

Some participants were more involved in the activities than others, especially as I met some people who had only just started the project at the time of interview. Particular activities come out strongly such as the exercise classes at Freedom Leisure, Uckfield and the Wilderness Woods outdoors classes. However, as has been discussed at some length, the community had been strongly participating in other activities such as at Hurstwood View, Buxted Inn and Making Memories events at St Mary’s in Buxted.

**WHAT DID PATIENTS AND CARERS SAY?**

“(I would) like to see it continue.”

“Rotherfield St Martin is fantastic.”

“We think, we will have a go at that!”

“It keeps me going!”

“Exercise makes me feel better”

“Jo helped a man who didn’t want to come (to Wilderness Woods), then he really got into it!”
10. MOST PEOPLE WORRIED THAT THE GOLDEN TICKET MIGHT END AND RESPONDED NEGATIVELY WHEN ASKED WHAT LIFE WOULD BE LIKE WITHOUT IT

When asked, patients and carers responded particularly negatively about the prospect of the end of the pilot and extension of the Golden Ticket not coming to fruition. The responses demonstrate the full extent of peoples’ feelings related to their circumstances and how things were for them before the Golden Ticket. Clearly, the thought of no longer having the support and activities was distressing to participants given the extent of sadness in their responses.

WHAT DID PATIENTS AND CARERS SAY?

Direct responses when asked what life would be like without the Golden Ticket were:

“Dreary and lonely.”

“Tough.”

“Feel on your own and no one to talk to.”

“Boring, lonely and worrying.”
“Would make life more dull.”

“Would be very scared.”

“Life would be a lot harder.”

11. PATIENTS AND CARERS IDENTIFIED SOME IMPORTANT SUGGESTIONS AND IMPROVEMENTS

Many said that the pilot was excellent but some people made useful suggestions for the future, including:

- Using name badges at all times
- Access to specialist drugs advice
- Contact from a specialist available where required
- Offering training for carers.

When asked, respondents in the main answered that they couldn’t think of any suggestions, or for some it was too early to say. Those who did respond identified the following improvements:

- Better (more appropriate) winter activities
- Improve access to outdoors
- Clarity on who is coming for what (which member of the Golden Ticket Team is visiting peoples’ homes and for what purpose)
- Better transportation.
In observing activities and other gatherings, I was able to learn a great deal about how all elements of the service model had impacted people. This further enhanced any insights obtained during interviews. By being physically present at activities project participants began to recognise and trust me more. This became evident in their invitations to participate in say; Christmas Candle decorating or in the Physical Exercise class, where one participant exclaimed: “Get involved Adam! You can’t get out of it that easily!”

As a result of this I was able to witness first hand any changes and anything novel that occurred as a result of patients and carers participating in the Golden Ticket. People began to share with me in more depth their experiences of dementia and the Golden Ticket itself.

One such example of this was when I observed a conversation between a CCG member of staff and a patient in which I felt the patient didn’t want to be seen as a burden to the NHS (in terms of time or money). 9 Further such insights gathered from observation are summarised below.

1. A DEMENTIA COMMUNITY OF INTEREST DEVELOPED OVER THE COURSE OF THE PILOT

One of the key elements observed was the development of a community of interest centring around the café first and foremost. A community of interest is a group of people who create a social network around a shared interest – in this case, dementia. Jo (from Rotherfield St Martin) would enthusiastically make conversation, introduce people to one another and make the necessary connections to help people feel involved.

At least half of the patients in the Golden Ticket participated in most of the cafés and activities. These activities became something to look forward to and where people could socialise, talk, share experiences and support each other.

9 This finding explains why question 4 of the patient and carer interviews asks: ‘Has the project helped you, or do you think it will help others’, because peoples’ opinion as to whether it would help others may well reflect their own perception as to if it has helped them.
Photograph 5: The Dementia Café in full swing

The community of interest stretched beyond the realms of the café and activities with carers volunteering to give other patients and their carers lifts between events and some becoming very close. One particular carer couple volunteered at the exercise class and later became employed as part of the Rotherfield St Martin activity coordination.

2. THERE WERE DIFFERENT LEVELS OF ACTIVE ENGAGEMENT WITHIN THE GOLDEN TICKET COMMUNITY

In terms of the development of the community as mentioned above, there was a strong sense of people participating in the activities and cafés fairly quickly from the beginning of the pilot. Thus suggesting a great need people had for them or for connecting with peers.

The community of interest developed into a fully supportive, developed community over the course of the pilot. At the beginning the Buxted Inn Café session had only a handful of participants, but just over three weeks later this had risen to at least 12-14 participants. By the end of the pilot it was packed full with patients and carers, with a jovial atmosphere and with everyone talking to each other and even singing Christmas songs to live music.

That withstanding, I noticed differing levels of engagement within the Golden Ticket community. There were some who were active participants, some who participated only occasionally and some who participated passively.
There was a group of around 11-12 dedicated participants who attended all of the activities and additional events. This group represented the majority, though there were a number of people who participated on and off during the pilot. Interestingly, there were others whom I interviewed who simply stated they were glad the Golden Ticket was there for them when they needed it and appeared to be passively participating as a result. For those passive participants I heard from people that they felt they had enough support on their own, for example they had live-in care.

There were others who appeared to not want to participate for another, often unknown reason. One case in point was a couple who said the Golden Ticket and its activities weren’t for them and that they had their own life. Even still, I later observed them attending a few activities.

Even though I observed the Golden Ticket vastly improving participant’s wellbeing, this highlights the complexity of the ways in which people chose to participate. Consideration must be made as to what can be done to ensure that the occasional and passive participants are able to become active participants.

3. PEER SUPPORT AND A RECIPIROCAL COMMUNITY ENHANCED PEOPLE’S EXPERIENCE AND EMOTIONAL WELLBEING

A voluntary reciprocal community had grown up between a large number of participants which was demonstrated in several ways including, but not withstanding: lift sharing, socialising outside of the activities and people looking out for those who hadn’t got a carer by visiting and keeping in touch. I observed people opening up to each other about their experiences and sharing advice and comforting each other. In a sense, participants began supporting each other outside of the boundaries of the project.

I observed two particular participants; Sally-Anne and Shirley - who had been living with dementia without any live-in support or carers. These patients were at risk of being socially isolated but the Golden Ticket offered them the chance to be a part of the reciprocal community. They were both very active in the activities and became close friends as a result of socialising at organised events. Both Shirley (see case study below) and Sally-Anne both reported substantial improvements in their wellbeing, largely because of the impact that socialising and feeling supported had on their day-to-day lives.

One person opened up to me about how the Golden Ticket had enhanced their emotional wellbeing. I met John at Wilderness Woods in December 2015 and as we walked he explained to me how dementia had affected him in comparison to his previous life. He said, “I was a bobby in Uckfield… I was used to being the boss! I have a marvellous wife, I do it (participating in the project) for her, life goes on…”

There were interesting reflections in my notebook that day too:

The event was good for people to meet and share experiences new and old. The coming together in numbers, in community, was clearly of great comfort to people affected by memory loss and their carers – there was laughter and chatting, with people asking about one another. Jo stimulates conversation as usual – contacting people to ensure their on-going involvement. It is clear that people know each other as a result of Jo being a ‘connector’, here is a ‘social cross-section’ that might not have otherwise met.
4. COMMUNITY CONNECTORS

The roles performed by Jo in the Rotherfield St Martin activities and the shared role she played alongside Jennie and Alex from Know Dementia at the Buxted Inn café, were the social bonding activities that connected the participants of the community.

Jennie was mentioned each and every time I interviewed patients and it appeared that she was seen almost unanimously as someone who was caring, trusted and knowledgeable. Indeed, in my own experience, Jennie and husband Alex worked tirelessly to inform patients and to guide them through the pilot and assist in signposting and sharing knowledge of other services available to them.

Every time I visited the cafes or activities Jo would be busy introducing people to each other and currying up morale, such as at the café with Christmas singing she would be handing out song sheets and encouraging everyone to participate. Similarly, at the Christmas ‘Making Memories’ event at St Mary’s Church Hall, Jo had gone to considerable lengths to ensure a full on Christmas party was enjoyed on a Saturday afternoon with sherry, song, oral history and mince pies.
On reviewing my notebook from the event I find the following reflections useful for the concluding session:

Shortly after I arrive and as the Sherry is passed around Jo exclaims, ‘Golden Ticket Christmas Party – Hurrah!’ The afternoon starts with Christmas Songs and Jo asks Brian, who has become quite popular in the group (to say the least), what instrument is playing to which he responds with much amusement: “Well, I did know, but I have the same excuse as everyone else in here for not remembering!” As I look around at all the smiling faces, I am in a privileged position as an evaluator as I have witnessed first-hand the personal story both in interviews and as in observation. As the project evolves and as the community and personalities develop organically, rich insight is also obtained by reflecting on the personal journeys and the tapestry of mechanisms at play, juxtaposed against the backdrop of healthcare professionals who deliver their care.
CASE STUDIES

I followed up findings with four case studies based on each individual story and issues were each reflected as potentially emblematic of themes arising more widely in the project. I was able to learn more about the background of people's lives and the effects of and impact of dementia over time on them and their families.

It also provided a fantastic opportunity to learn more about suggested improvements for the future and also any case specific issues such as on medication, the ‘BLIP’ clinic or appointments. Themes arising from interviews and observation were also tested when producing these case studies.\(^\text{10}\)

SHIRLEY SMITH

I first interviewed Shirley on 1\(^{\text{st}}\) November 2015 and followed up for a more in-depth case study interview on 19\(^{\text{th}}\) December 2015. Shirley had only been involved in the Golden Ticket for a matter of weeks when we first met and I subsequently met her at every other event I observed or participated in. Shirley was an active and central member of the Golden Ticket community and it was clear at the outset that she had personally greatly benefitted from the service. In our conversation, she stated that:

“I want to live and to enjoy it now rather than prolong it if that is how it is going to be.”

Shirley lives alone and has had to manage with dementia related memory loss for the last 2-3 years, largely on her own, though her daughters have visited in that time. Shirley told me that she likes to stay positive and be proactive, which is why she visited her GP who immediately referred her to the Memory Assessment Service in Crowborough. Her memory was scored low but her cognitive function was high. Unfortunately, Shirley also suffered negative reactions to the drugs she was prescribed.

Early involvement in other dementia support groups proved largely unfruitful for Shirley. She found classes and exercises for people with dementia to be impersonal and attendees to be uncommunicative at times. Other activities hosted at another dementia service in in Uckfield were attempted as part of dealing with her diagnosis. However, Shirley felt that paying for day care was too much and felt alienated from people ‘sat around in chairs, with a slumped face (who were) way past talking to me’ and decided it wasn't for her.

Shirley was referred on to the Golden Ticket by Dr Costello after she had a fall. She was very excited to be involved. Her experience was in stark contrast to her earlier involvement in dementia activities. Now Shirley feels excited to be part of the Golden Ticket, looks forward to participating in events and even volunteers at the café so she can talk to people in attendance. Through participating Shirley has found friendship. She said “lots of us are very close. I always think, oh, I am on my own, but hearing others seems to help.”

\(^{10}\) For a list of questions asked in case study interviews, please refer to Appendix 2.
As a result of participating in the Golden Ticket Shirley claims she feels more alive but this is mixed with negative feelings as she notices her condition deteriorating. The Golden Ticket staff are “all fabulously caring” in her experience and “everyone who runs it are lovely”. The only improvement she recommends would be for memory strengthening activities to be introduced.

Shirley is beginning to talk about the future with her daughters. She recognises that “it would be silly to be on my own. I need carers”, but she is against being in a home. The Golden Ticket offered Shirley the opportunity to actively participate in a wider community, attend wellbeing interventions and benefit from the reciprocal community, thereby reducing chances of social isolation and improving her wellbeing. She really hopes the Golden Ticket continues.

Photograph 7: Shirley cooking at Wilderness Woods
I first met Peter and Barbara in their home on 16th October 2015. They had been caring for Peter’s mother, Dilys, who had been living with dementia for some time. It was my first interview and I later found them to be representative of many others who care for a person with advanced dementia in their own home.

They had an extension built as to ‘not let our mother need to go into a home’. When I met Dilys in her flat I noticed how detailed her memory wall was, with many members of family. As Barbara mentioned, she “likes spending time in her own space… we move with what makes her feel comfortable”. The Calders saw that although Dilys spends time alone it is important that she eats with them as this is a communal time.

It came across very clearly that the Golden Ticket would be useful for them when I first interviewed them in October 2015 even though they were relatively new to it. When I went to visit the Calders in their family home over the Christmas period to interview them again as case studies they offered me lunch by claiming, “You’re part of the family now!”. This was an opportunity to ask more about how Dilys came to be diagnosed.

“We kept very close to Mother when she was in Liverpool. We knew that memory loss was apparent as conversations repeated and when we provided information it was not retained. We decided to extend the house several years ago and Mum moved here. Over the last 8 months her ability to function (other than keep memories of the past) diminished, so we decided to go to the GP and then on to the Memory Assessment Service at Uckfield for diagnosis.”

“We would have said that Mother was between 8-10 on a scale and the Memory Assessment Service said she was moderate. It wasn’t until we met others in the Golden Ticket that I understood this to be true.”

“We have found it immensely beneficial - probably more than Mum has! Understanding what lies ahead, the supportive nature of Know Dementia, Dr Costello, Rotherfield St Martin and everyone involved in the pilot helps.”

When asked what could be done to improve things, Peter noted that there is duplication between the Golden Ticket and the work of other organisations such as Care for the Carers, the Red Cross and so on. Peter felt that a refinement, a simplification of information is needed and suggested that communication should be face to face or over the phone. He also said “some people do not have a carer - then what?”

“The project has been an astounding success - we would view it as a loss (if it were to end). The café helps people to swap ideas and information, there is a good atmosphere there and a community has built up around it and the interventions.” That said, Peter did raise concerns about engaging people who were not part of the ‘usual suspect list’ - “same faces at the café - not the whole forty (participants).”

Peter became more and more involved in the Golden Ticket pilot - as a volunteer and later as a paid employee of Rotherfield St Martin. He took over the role of Activities Coordinator and reflected by saying “I get pleasure from helping people and seeing them enjoy
themselves.” Barbara also got more involved and was asked by Jo to help with the exercise classes to help patients, to which she kindly obliged. She said: “I enjoy a laugh and the interactions. Unless people do volunteer, it isn't going to be available.”

Barbara and Peter’s case demonstrates the importance of information, advice and support for carers. Their story shows that carers have huge potential to be actively involved in dementia support communities and can offer unmatched levels of reciprocal support.

Peter said “it would be a cardinal sin if the Golden Ticket was prevented or didn't happen in other CCG areas… I haven't met anyone who hasn't said that it hasn't transformed their life…”

Photograph 8: Peter at an exercise class at Freedom Leisure
When I first met Brian and Betty Lewington on 14th November 2015 I was struck by Brian’s humour when he said “half of her brain is for my use anyway - it is part of being a carer!” Brian had been living with dementia and was being cared for by his wife, Betty. He expressed his concerns about his wife and other carers and said “I appreciate the fact that carers are involved in the Golden Ticket and I worry about those who do not have a carer.”

Before his diagnosis Brian had been self-employed and ran a plant nursery. A friend had recommended the Golden Ticket to him and suggested that he might volunteer himself onto the pilot. Brian came to be a star member of the Golden Ticket community and is extremely popular. His wife Betty explained that it “brought him out of himself - like his old self again.”

In my observation, he became close to many other patients and carers, especially through his ability to sing exceptionally well and his endearing humour. In a café in mid-December I recall upon his arrival a participant shouting “heeeere comes Brian!!” Joyously to the delight of the room. Betty and Brian have made many friends in the Golden Ticket community.

Photograph 9: Brian and Betty Lewington

11 Please see Appendix 4 for a written contribution to the service evaluation, hand written by Brian Lewington for this report.
They do admit that they have “gravitated to the same group - we don't mix as much with new people.” This correlates with previous findings that those who were actively engaged in the pilot came to be very close with each other. Brian and Betty felt that more could be done to engage and encourage others to actively participate in future iterations of the pilot.

Brian wrote me – by hand - some heartfelt, touching feedback about his and others’ experience because he was so passionate about what had been delivered. The letter describes how he longed for normality and how the service had enabled him to be so. He worries about getting a lot worse with his condition but he says he is “not as bad as he was… I (now) get input from other things… the Golden Ticket has helped me to socialise”. Amongst the things that Brian enjoyed particularly were the café sessions and physical exercise classes. Of the latter, he said “we know there are limited numbers but we aren't turned away.”

When asked about the future Brian said “I hope it continues, I hope I don't go completely nutty or ga-ga. I want to keep my mind active; I have to have a reason to get up in the morning. I have found it (the Golden Ticket) really useful and I have met a good crowd.”
KATHLEEN GORE

I first met Kathleen Gore who cares for her husband Jack, who lives with severe dementia, in early November 2015. She informed me that her husband wouldn't be able to respond to the interview questions. Kathleen has power of attorney for Jack, who received his diagnosis back in 2013. Kathleen informed me early on that they had received a lot of support over the years. “We can pay for carers - we have a live in carer and night carer too.”

What was particularly interesting about Jack and Kathleen’s story was that although the Gore’s were able to support themselves, having the Golden Ticket in the background should they need it was helpful. She said “there is somewhere I can go to (for help), it is more obvious now.”

According to Kathleen, Jack had displayed challenging behaviour as a result of his condition and had previously hit a night carer. Kathleen had contacted the nurse specialist who suggested a prescription of Temazepam to help him sleep at night. I asked Kathleen about how it felt to be a carer for someone who has dementia:

“When you don’t know what is happening you are in a tailspin. It is difficult giving up privacy and letting others do things and I know it is hard because he prefers me doing it...Jack wants his wife and no one else.”

When asked about how the Golden Ticket had featured in their life, Kathleen explained: “Jack is partially blind and deaf. He has never been one to mix with people - he won’t go to a circle and sing songs, he isn't a typical case and we can't take full advantage. We have gone to a couple of coffee mornings and he has been enjoyable and polite. His idea of time has gone and has no idea what time of day it is.” She also said “lots of people care and show they care. They show their support which is very, very, valuable. The whole package is very, very, good and that feeling of support is gold.”

Kathleen’s story shows that the Golden Ticket delivers huge benefits even for those who do not actively participate in organised activities. It also demonstrates faster access to medical support can be hugely beneficial in difficult circumstances.
FINDINGS: THE STAFF EXPERIENCE

Both healthcare professionals and third sector partners worked in parallel in the delivery of the Golden Ticket pilot. I set out to understand more about what they thought about the project, lessons learned, suggestions for improvement, and if it had improved patient experience.

I collected data from staff in the first instance using an e-survey and later using semi-structured interviews. Where possible, interviews were face to face or else conducted by telephone. These interviews formed the basis of staff insight highlighting interesting areas for improvement for future service development and deployment.

KEY FINDINGS

Findings are set out in three key areas covering patient experience, issues and solutions for improvement of the service for future delivery.

1. THE GOLDEN TICKET IMPROVED PATIENT EXPERIENCE

Staff largely reported that they thought the Golden Ticker was ‘better for the patient’ and enhanced patient experience. Some points raised by staff when asked whether the Golden Ticket had improved patient experience are presented below.

WHAT DID STAFF SAY?

“Very much so – one lady (recently deceased) was housebound and for the first time (she) was able to get out and about with her husband – a wonderful gift!”

“I thought it gave patients and carers a (chance) to be open and say things they wouldn’t usually say (e.g. depression and withdrawal); and I could check with the carer as to whether they were in agreement with what the patient was saying or not.”

“Patients felt abandoned before the clinics started and they didn’t know where to go. Now they feel relieved.”

“Very beneficial to patients and carers. One person said ‘I can’t believe that so many people are looking after me.’”

“I’ve only received positive feedback from patients and carers – having someone spend time to listen and take care. This is the missing bit. As a clinician this is challenging due to complexity, but I like it. Lots of clinicians feel they can’t do it – it requires a team effort as it’s not always a clinical issue. We need to be looking at the patient and carer holistically.”

12 See table 1 for list of Health Care Professionals (HCPs) and providers of services.

13 See Appendix 2 for a list of questions asked in interview with HCPs and providers.
“Many congratulations to those that put this together, (it is) very inspirational.”

“I think so, from what I’ve seen – especially having it locally and for people to pop into the surgery but I’m not sure how to replicate this in say, Newhaven.”

“It’s a nice opportunity to build up relationships and for peers to engage and socialise with each other – it’s been a really good model.”

“The whole system approach; working with the carer and being community based, are all fantastic, but how does this extrapolate to the wider population? I can think of GP practices that could be tricky, especially if there aren’t any third sector organisations there.”

“Even those who didn’t want to be a part of it are now joining in. Everyone involved has been touched. All have engaged in some way or another. Socially isolated people are encouraged and are joining in.”

2. ISSUES

Staff were able to identify a number of issues that should be considered for further roll-out of the Golden Ticket project. These are set out as six themes below.

TIME

• There is not enough time to perform existing roles alongside the Golden Ticket role
• Not enough time to prepare in advance for the Golden Ticket
• Trying to see all patients as quickly as possible and coordinating patient meetings and activities is time consuming
• Home assessments are not as resource efficient as clinics.

COMMUNICATION

• Communication between Primary and Secondary Care is not currently effective and there was a lack of understanding and clash of clinical perspectives
• Inability to sync Primary and Secondary Care information systems and difficulty in sharing information between organisations (including the third sector) about patients in advance
• No third sector representative on the Multi-Disciplinary Team, this meant a missed opportunity to share information
• Too many people contacting patients and carers at once
• Difficulty in obtaining consent multiple times.

EDUCATION AND TRAINING

• Provide education and training to all participants including staff and carers before the go-live date
• Lack of understanding of each other’s roles in pilot, for example, duplication of the Golden Ticket Guide (Know Dementia) and Social Worker role.
FINANCING

• Difficulty in securing backfill cover for Primary Care staff
• No incentive payment for practices
• Funding is needed for extra resource to deliver
• Less socially advantaged people were identified as less likely to participate.

LOGISTICS

• Length of pilot was limited
• Not all patients got the full Golden Ticket experience.

CARERS

• Some carers are not supporting patients in activities when they need to
• Patients sometime arrived at activities earlier than the start time and were unaccompanied
• Challenge of carer stepping in during assessments at home.

WORKFORCE: A GPS PERSPECTIVE

UNIVERSAL APPROACH TO DELIVERY

One GP at Buxted Practice felt assured that the Golden Ticket was an idea that came from GPs. The pilot was designed by GPs, for GPs—“this has developed from a tiny seed of an idea and has been formed into a tangible, workable model with our needs in mind”. It was important to the GP that other practices considering adopting a similar approach are aware that the model can be delivered by any practice without the need for specialist input:

“There is a comprehensive, continuous support package that doesn’t require lots of GP time. We work with allied health professionals who are able to provide us with far richer information on the patient than I would ever get in a 10-minute consultation. It’s as if I can then act as a GP consultant – this is how we can reduce the overall workload”.

EMPOWERING GPs TO GIVE THE BEST POSSIBLE CARE TO PEOPLE WITH DEMENTIA

Another GP at Buxted Practice said that the Golden Ticket had enabled her to have better quality consultation time with patients. This is because other concerns that the patient had were addressed and managed well in other parts of the system.

“This is about being proactive rather than reactive. The patient knows best what to do; where and when to go to appointments, or community interventions. When the patient comes to us as GPs, we are there to do what we do best.”

“The joined up approach that the Golden Ticket model encourages benefits everyone involved. The practice is at the heart of the project – but now it isn’t all about the GP.”
3. IDEAS FOR IMPROVEMENT IN THE FUTURE

PRACTICE STAFF

- If there are going to be less staff on duty at the practice there needs to be the right facilities in place and for staff to be flexible
- Pharmacy should be built into the service as GPs do not have a huge amount of time to do medicine reviews\(^{14}\)
- When staff were used for the BLIP clinic, colleagues thought they couldn’t be used (for other work) as they were CCG funded
- Allocate time slots for Golden Ticket clinic\(^{15}\)
- Longer time slots for Golden Ticket and more training for practice staff about roles, work plans and dementia
- Funding for resources to cope with additional workload in practice for example, when receptionist calls patients before appointment
- Provide emotional support for patients and carers
- More education for all (carers, patients, family, staff and children) to challenge stigma early on about dementia and how the Golden Ticket can help.

THIRD SECTOR ACTIVITIES AND SUPPORT STAFF

- Having the third sector present at the Multi-Disciplinary Team would add value
- Having a single coordinator\(^{16}\) to call patients about activities, appointments and support roles
- Information about patients should be received before they attend activities to be able to be equipped to deal with a range of abilities
- Training for all staff\(^{17}\)
- More volunteer helpers for exercise classes to cope with demand and capacity
- Golden Ticket Guide to visit and arrange Occupational Therapist, Social Worker and other supporting roles
- Prioritise people whom most need attention at medical centres
- There should be clarity on case load in advance of start date.

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\(^{14}\) “patients are often taking less suitable medication and dosage as well as not understanding the side effects. Reviewing issues helps us to be smarter – to see what is best for the patient” (Practice Pharmacist)

\(^{15}\) “running to time is almost impossible, some are quick but others are late due to getting the patient ready. Carers would often open up (emotionally) mid flow and it is hard to keep to time” (GT Clinic Lead)

\(^{16}\) to avoid patients being overwhelmed by multiple contact

\(^{17}\) “we had to explain situations, anxieties and let people know about the group” (Freedom Leisure activity leaders)
SECONDARY CARE – SUSSEX PARTNERSHIP NHS FOUNDATION TRUST (SPFT)

- Be better at being a single team with inclusion of third sector at MDT
- Make the consent process less confusing for staff and patients\(^{18}\)
- Shouldn’t need to record patients in the CPA system
- Involve Secondary Care in the wider intervention offer
- Base all MDT clinics at the host practice
- Include a Nurse Prescriber role as part of future BLIP clinics
- Be clear on what costs are required to cover capacity and demand
- Be better at sharing information
- Ensure clinical supervision for third sector staff
- Post graduate training for Clinic Lead in practice (more than a dementia diploma)
- Diagnose in Primary Care with Secondary Care present.

SOCIAL WORKERS

- The Golden Ticket does not require a dedicated Social Worker. Instead, a Social Worker could be used through referral by Practice, Know Dementia or Care for Carers.

\(^{18}\) Confusion about repetitive consent process in clinic and at practice.
PART FOUR: CONCLUSIONS AND RECOMMENDATIONS

A RECIPE FOR SUCCESS

Based on my experience of the pilot’s success and bearing in mind the potential future roll-out of the service, it is worth bearing in mind several key elements or ‘ingredients’ worthy of consideration. This section represents a list of recommendations for future service delivery.

LOCATION

A town or city may place different demands on the service than a rural location and service design must be sensitive to each location. Service design must also take into consideration whether areas of higher deprivation require different approaches to engagement, promotion and/or additional support for involvement compared to wealthier areas.

PRACTICE SUPPORT

Primary Care support is crucial to the successful delivery of the Golden Ticket service model. Practices will suffer varying degrees of pressures on their time and resources and some may require additional training, facilitation, backfill and the presence of a Dementia Champion.

COMMUNITY AND PRIMARY CARE SUPPORTING TRANSPORT NEEDS

Transport was clearly of vital importance in a rural area such as Buxted and its surrounding villages. It was extremely lucky that Buxted Medical Centre were able to provide a mode of transport for participants. Other areas adopting the model will need to consider this.

CCG PRESENCE AT THE CAFÉ – PROJECT SUPPORT OFFICER

Having The CCG’s Project Support Officer present at the Buxted Inn Café was a useful bridge in such a collaborative, multi-agency project as the Golden Ticket. Future cafés could also benefit from this, although this will be resource intensive.

A JO (OR PETER) THIRD SECTOR COORDINATOR ROLE

Right from the outset Jo had been heavily involved in the development of the community of patients, carers and members of staff as named Activities Coordinator. By introducing people, raising morale and starting conversations at every event, Jo had enabled the right connections to be made for the community to thrive outside of interventions and activities.

A JENNIE AND ALEX (KNOW DEMENTIA) – THE DEMENTIA GUIDE ROLE

Jennie and Alex were the safe pair of hands that were needed for patients and carers to feel that they had someone to contact on issues they were not sure about. Both worked tirelessly to ensure that patients and carers felt supported and acted as the Golden Ticket ‘navigators’.
CONCLUSIONS

The qualitative service evaluation was conducted with key frames of inquiry. A summary of insights and conclusions against these themes are outlined below.

1. QUALITY OF LIFE FOR PATIENTS LIVING WITH DEMENTIA

The quality of life for patients and indeed carers of people with dementia had evidently improved as a result of participating in the Golden Ticket. In interviews, responses demonstrated that the service before the Golden Ticket was inadequate and caused some level of stress for people accessing it.

Once people had joined the Golden Ticket they largely reported that their experience was better than before. They felt more secure with having access to the Golden Ticket Guide (Know Dementia) and the wellbeing interventions were something to look forward to. The community that built up around it and later the reciprocity of volunteers and peer support has benefitted people’s quality of life significantly.

2. ABILITY TO LIVE INDEPENDENTLY

It was clear that some people had a sense of pride regarding their ability to live independently and did not want to be seen as ‘sponging’ from the NHS. Even so, people did report that they felt more supported and/or believed that the Golden Ticket could help others. Carer involvement also allowed them time to stop, obtain respite or simply enjoy the benefits of meeting their peers and socialise. When carers are supported well with greater independence, patients will be better cared for too.

3. ACCESS TO INFORMATION AND ADVICE

It was originally envisaged that the Handbook would be the go-to place for information and advice for participants. Though, people reported that it was not as useful as it could be. Recommendations for improvement have been made outside of this report\(^\text{19}\). However, people did say that they found it easier to access information and advice via other channels, namely via the guide role, peers and the activity coordinator(s).

There was evidently an important need for carer information, support and advice. Carers were so willing and had such a strong sense of duty of care for their loved ones, that some even requested dementia-specific training to be able to do their role better.

4. OUTCOMES OF A RANGE OF WELLBEING INTERVENTIONS

Both patient and carer experience improved as a result of being 'held' within a robust and active community, largely centring around the Buxted Inn Café and the Rotherfield St Martin wellbeing interventions. The biggest reported impacts of the Golden Ticket were the wellbeing interventions, peer support and opportunities that arose to socialise with others.

\(^{19}\) Adam Gill Projects Ltd facilitated an ‘Open Space’ event with Staff and Patients to obtain solutions and further enhance the project.
Jo, who led the wellbeing interventions, acted as a community connector by enabling people to make conversation and ultimately strengthen peer network, and build a supportive community.

5. MENTAL HEALTH AND WELLBEING FOR PATIENTS AND CARERS

People’s sense of wellbeing improved as a result of participating in the Golden Ticket, especially because they felt better supported and was part of a wider community. Such was the positive impact of the project, that when asked how they would feel if it ended most responded that it would be terrible if it did. This demonstrates just how important the service had become for people with dementia and their carers. This was especially the case for patients whom lived alone without carers and were at risk of becoming socially isolated.

For those participants who accessed the service occasionally or passively, the benefit was that the project was there should they need it or that people were comforted to know they could access more parts of the service if things got very bad for them.

6. CARER EXPERIENCE AND OUTCOMES AS A RESULT OF PARTICIPATION

According to a 2016 report on the impact of dementia on carers within existing care models20, ‘caring for someone with dementia puts a huge strain on the carers physical and mental health as well as straining, at times to breaking point, the relationships with other family members.’ The report also demonstrates that ‘carers of people with dementia feel socially isolated’ and face other stresses such as work/care balance resulting in financial loss and additional stress (2016:31, 36).

Carers reported high levels of peer support stemming from their involvement in the Golden Ticket. For them, sharing experiences and understanding more about the condition from others helped people to feel they weren’t alone. Friendships were then developed on this basis. Such was the reciprocal community that developed, some carers even wanted to volunteer or otherwise take paid employment for the future of the Golden Ticket.

7. WORKFORCE PERCEPTION OF SYSTEM IMPROVEMENTS

Although staff reported several significant issues, these were posed in order to refine the service model for the future. Staff members widely reported that the Golden Ticket pilot had improved patient experience. In particular, they reported that having third sector partner ‘eyes and ears’ on the ground and Primary Care staff working closely with them was best for the patient.

A Multi-Disciplinary Team (MDT) approach has been a successful element of the pilot. So much so that members of the MDT had requested greater input in team meetings from Know Dementia in the future. As there is a joined up approach, a more connected community and greater involvement of carers; responses when things go wrong should be dealt with more rapidly.

Although the BLIP clinic was not used often during the time span of the pilot, it could well be used more often. It is a useful example of how a joined up, person-centred model can support patients and carers more rapidly. This approach also enables carers and families of those people with dementia to live better and enable those they care for live with dignity.

A Royal College of General Practitioners (2014) study of Primary Care patient-centred approaches suggest that these can ‘improve health outcomes and quality of life for patients, as well as reduce avoidable demand for health and care services.’ Feedback from the Golden Ticket has demonstrated that this person-centred dementia care model has influenced: improvements in quality of life for both patient and carer; improvements on mental wellbeing; and provision of care, which could reduce avoidable demand on services such as A&E.

**IMPLICATIONS FOR FUTURE MODELS OF DEMENTIA CARE**

Robert Putnam (1993) developed a theory of *social capital* that offers a view as to the inter-related roles of: a) the extent to which citizens are engaged in their communities and b) the impact this has on how governments and other social institutions (such as NHS) perform. Putnam (1995) also highlights that ‘social trust’ exists in this transaction, which according to Blanchard and Horon (2000: 6) is derived from: 1. Norms of reciprocity, in which ‘there is a belief that good acts or pro-social behaviour will be reciprocated by participants’ and 2. Networks of civic engagement, that ‘encourage social trust and cooperation’ to develop.

When applied to the experience of patients and carers in the Golden Ticket, it is clear that given the space to form a community, develop peer support and trust, a more advanced and reciprocal community has developed wherein participants are supporting each other out side of the confines of the Golden Ticket forum. Evidently, a person-centred model of care for people with dementia is best delivered within an active community involving third sector, Primary Care, and Secondary Care partners. In facilitating this, support received is reciprocated by patients and carers thereby creating a two-way system of person-centred care.

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BIBLIOGRAPHY


LIST OF APPENDICES

Appendix 1 – Golden Ticket Partner Organisations

Appendix 2 – Patient, Carer and Staff Interview and Case Study Questions

Appendix 3 – List of Observed Activities

Appendix 4 – Written letter by Brian Lewington
### Appendix 1 – Golden Ticket Partner Organisations

<table>
<thead>
<tr>
<th>Partner Organisation</th>
<th>Role</th>
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<tbody>
<tr>
<td>Buxted Medical Centre</td>
<td>Golden Ticket host GP Practice for Review Meetings and BLIP clinic for any unexpected ‘blips’ patients may experience</td>
</tr>
<tr>
<td>Buxted Medical Centre Pharmacy</td>
<td>Pharmacy Reviews</td>
</tr>
<tr>
<td>Sussex Partnership NHS Foundation Trust</td>
<td>Memory Assessment, Management and Crisis Service, hosted by the Multi-Disciplinary Team (MDT)</td>
</tr>
<tr>
<td>East Sussex County Council</td>
<td>Golden Ticket Social Worker – specifically assigned to the case load identified for the project, also attended the MDT</td>
</tr>
<tr>
<td>Rotherfield St Martin</td>
<td>Third sector organisation responsible for coordination of activities and interventions coordinator (e.g. Wilderness Woods)</td>
</tr>
<tr>
<td>Know Dementia</td>
<td>A third sector organisation that provided the Golden Ticket ‘Guide’ role that offered advice and signposted to other services, as well as carrying out advanced care planning</td>
</tr>
<tr>
<td>The Buxted Inn</td>
<td>A local pub/bed and breakfast that hosted the Peer Support Cafe and later became a hub for many Golden Ticket activities including Know Dementia talks and workshops</td>
</tr>
<tr>
<td>Care for Carers</td>
<td>Third sector organisation proving support and signposting for carers, though this support was not specific for those involved in the Golden Ticket</td>
</tr>
<tr>
<td>Wilderness Woods</td>
<td>Hosted outdoor activities for groups of patients and carers, for example the making Christmas decorations afternoon</td>
</tr>
<tr>
<td>Hurstwood View Residential Home</td>
<td>Care home hosting craft mornings for GT patients and carers</td>
</tr>
<tr>
<td>Freedom Leisure</td>
<td>Offered a weekly low intensity, fun and interactive exercise class specifically for patients involved in the Golden Ticket pilot</td>
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<tr>
<td>Carers Breaks Dementia Engagement Service</td>
<td>Providing personalised support guidance and respite.</td>
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<tr>
<td>St Mary’s Church Hall venue</td>
<td>Making Memories events were held at this venue</td>
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<tr>
<td>High Weald Lewes Havens Clinical Commissioning Group</td>
<td>Commissioning organisation</td>
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<tr>
<td>Adam Gill Projects Ltd</td>
<td>Qualitative Service Evaluation Lead</td>
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</table>
Appendix 2 – Patient, Carer and Staff Interview and Case Study Questions

1. What was your experience of care and support for the person you care for before now?

2. Do you prefer this service now?

3. How has your experience changed since participating in the golden ticket?

4. Has it helped you / do you think it would help other people?

5. Is there anything that could be improved?

6. Is there anything that is missing from the service?

7. When were you/ was the person you care for diagnosed? – what was the experience like?

8. Has the handbook been useful to you so far/ (have you used it)?

9. Has it been easy to access information and advice as a result of participating in the golden ticket?

10. Do you think the person you care for can live more independently as a result of participating in the golden ticket?

11. How do you feel as a result of participating in the project and in what way?

12. Do you feel more supported?

13. Do you feel that you can continue in your caring role for longer, with the help and support of the golden ticket?

14. What has been your experience of the ‘guide’ role of Know Dementia?

15. Do you know who to contact in times of difficulty?

16. What ‘bit’ of the golden ticket has made the biggest difference to you and your quality of life?

17. If you didn’t have the golden ticket, what do you think life would be like in the future’?

18. Have you participated in any of the activities that Rotherfield St Martin has coordinated? What has been your experience of these?
### Appendix 3 – List of Observed Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Location</th>
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<tr>
<td>Buxted Inn Cafe</td>
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<td>Buxted Inn Cafe</td>
<td>Buxted Inn</td>
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<tr>
<td>Wilderness Woods Christmas Decorations</td>
<td>Wilderness Woods</td>
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<tr>
<td>Making Memories</td>
<td>St Mary’s Church, Buxted</td>
</tr>
<tr>
<td>Physical Exercise</td>
<td>Freedom Leisure, Uckfield</td>
</tr>
<tr>
<td>Hurstwood View</td>
<td>Hurstwood View Residential Home</td>
</tr>
<tr>
<td>Open Space</td>
<td>Buxted Inn</td>
</tr>
</tbody>
</table>
Appendix 4 – Written Letter by Brian Lewington

We met at house parents at the Wilton Park School for Spastics
in 1960 so my wife had good experience to suit her as a Care
for an old man with dementia. We share her brain and
abilities to do two of gardening and fruit juice.
She answers the telephone and files in lots of forms. I really
need someone else to act as a chauffer to do the
ingraining and cook the meals. Seriously, carers are very
important and we don’t mind if they use child psychology
to get us to be good.

We have been off for 2 weeks and missing
the activities. And chatting to our friends.
We talk on things like how things used
to be and rabbiting with friends – just as any
one else would. The empathy comes from
our common though different symptoms
I forget what they were are.