



The Debenham Project: Evaluating the Provision, Availability, Cost, and Quality of Health and Social Care for Older People in a Rural Community - May 2022

Dr Ruth Strudwick

Associate Professor; University of Suffolk



Contents

1.	Foreword by Lynden Jackson (Chair of the Debenham Project)	3
2.	Introduction	4
3.	Data collection	5
4. Lov	Statistical Information and Data Analysis - Overview of the results (Highlights and vlights)	5
5. que	Information from patients, service users and carers about current services via a estionnaire and a series of focus groups	8
5	.1 Questionnaire	8
5	.2 Focus groups	9
	Table 1 – Themes and sub-themes from the focus groups	10
5	.3 GP services	10
5	.4 Hospital services	12
5	.5 Social services	12
5	.6 Community and support services	13
6.	Conclusion	15
7.	Postscript by Lynden Jackson (Chair of the Debenham Project)	.15
8.	Acknowledgements	16
9.	References	. 17
App	pendix 1: Primary Care	. 18
	Table 2 – Debenham Group Practice Patient Demographics	18
S	staffing at the Practice & services provided	
	Table 3 – Staffing at the Practice as at 01/01/20	18
	pendix 2: Hospital Care for patients within IP6, IP13, IP14 and IP6 9, IP13 6, IP13 7, IIP14 6, IP23 7 postcodes in the 2019/20 financial year	
Е	mergency Admissions	20
	Table 4 – All patients	20
	Table 5 – Patients with Dementia	20
Α	&E attendances from patients	20
	Table 6 – A&E Attendances	20
	pendix 3: Adult Care Services for clients in the postcodes IP6 9, IP13 6, IP13 7, IP14 5 4 6, IP23 7 as at 01/01/2020	
	Table 7 - Number of people receiving social care at home, different types of social cardomiciliary, very sheltered and high dependency	-
	Table 8 - Number of people receiving care in nursing homes whose previous address was within the Selected Postcodes.	
	Table 9 - Number of people receiving care in Residential homes whose previous address was within the Selected Postcodes:	21
	Table 10 - Number of people receiving day care services	21

Appendix 4: Community Health Care data for patients in postcodes IP6 9, IP13 6, IP13 7 IP14 5, IP14 6, IP23 7 as at 01/01/2020	•
Appendix 5: Mental Health Care data for patients in the postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 as at 01/01/2020	
Appendix 6: Local Support Groups and Activities data for the postcodes IP6 9, IP13 6, IP7, IP14 5, IP14 6, IP23 7 as at 01/01/2020	
Appendix 7: Questionnaire results	26
Appendix 8: Focus Group Questions	27
Appendix 9: Anonymous verbatim transcriptions of focus groups and interviews	28
Appendix 10: Place-Based Needs Assessment for Eye/North West Suffolk in 2017-19	28
Appendix 11: Statistical Considerations	28

Foreword by Lynden Jackson (Chair of the Debenham Project)

There is little doubt about the historical success and excellence of the NHS since its creation in 1948 – an overarching national organisation committed to a universal standard of health care freely available to everyone regardless of income or status. On the other hand, Social Care did not receive the same political and popular attention and support. Nevertheless, it has developed as a statutory responsibility of local authorities to provide support in the home, and care in residential settings for the vulnerable, elderly, and frail. Together, the NHS and the Social Services have become and remain the cornerstones of the social conscience of our society. However, they have never been the only contributors to our wellbeing. Probably, the most important influence on living happily and coping with the difficulties we all face as we get older rests within our community – our families, our friends, our neighbours, and those around us.

Over the past 70 years the pattern of our society has changed enormously and the advances in medical practice, technology, and pharmaceuticals have enabled us to live to significantly greater ages. But for many that involves coping with chronic ailments and increasing frailty. This has resulted in much greater demands on the health and social care sectors to the point of overload and potential failure. If the decline in the capability and capacity is to be reversed, this must be a decade of major change in which the way care and support of our growing elderly population in the community is provided must be a priority.

This was the context in which The Debenham Project recognised the importance of: Understanding the availability and accessibility (and costs) of health and social care at the personal level and, specifically, for those who live in, and contribute to, our own community: That the immense amount of data that is gathered about the NHS, the Social Services, and other agencies should be focused on, and made understandable to, the people who are using their services, and the communities they live in i.e. "Person-Centred" and "Community-Centred".

So, with the support of the Parish Council, we asked the University of Suffolk to research how to achieve a realistic picture of "The Provision, Availability, Cost, and Quality of Health and Social Care for Older People in a Rural Community" – specifically, Debenham and its surrounding villages. There were several reasons for launching this study. We believed that the results would inform/assist/advise in:

Understanding the strengths, weaknesses and potential in our community

Planning local resourcing to meet current/anticipated demand

Providing a model that can be used in analysing the potential of local initiatives

Creating a person-centred database of health, social care, and wellbeing support in and around the Debenham community

Enabling our community to express its wishes and argue for development with regard to our elderly residents

This is a research project - an exploration — which we hope will lead to greater local involvement in how health and social care responds to the needs of local older people. We know that it is "a first attempt" and, whilst by no means comprehensive, we believe it provides a realistic assessment that highlights a lot of the good and some of the not so good.

Of course, Covid-19 created a number of challenges, the most obvious being the delay of more than a year that it introduced into the programme, and maintaining momentum over that time. But the most important has been the dislocation of the normal operation of the NHS and Social Care which clearly must have substantially influenced the data provided by individual patients, carers, and other respondents to the surveys and discussion groups. Nevertheless, and overall, this study offers a "baseline" of the situation as it existed in March 2020. We would argue that, once the pandemic has finally run its course, the provision and accessibility of health and social care services will return to something like it was. Hopefully, lessons will have been learnt and a spirit of change will be supported at the highest level. I feel Debenham should seek to influence those changes based upon not only facts, data, and statistics but also upon the reality of the experience and testimony of its residents.

The report offers the evidence, numbers, analysis, <u>and</u> words with which to ask those who have to decide the future of the NHS and Social Care in Suffolk to place "Caring in the Community" as the central theme.

2. Introduction

This research project was commissioned and funded by The Debenham Project to identify and examine exactly what health, social, housing, charitable, voluntary, and community support is currently available to the older residents (aged 65 and over) of Debenham and the surrounding villages. This followed on from concerns that had been raised by the residents about services in their area.

Debenham, together with the surrounding villages covering the local postcodes; IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 has an overall population of approximately 8,842. Debenham itself had a population of 2,210 in 2011 (ONS, 2011). The village of Debenham provides access to a range of amenities including schools, shops, a small library, a leisure centre, two pubs, churches, sheltered accommodation, and the local General Practitioner (GP) surgery.

Regarding health and social care, other than the GPs and community nurses, there are local voluntary support services which are provided by The Debenham Project. Personal care is provided by remote care agencies together with a limited number of local self-employed carers. The nearest residential nursing home is seven miles from the village (with no direct public transport) in Framlingham. It is between eight and ten miles to the nearest extra-care

facility, in Stowmarket. Hospital and specialist health services involve travelling either 15 miles to Ipswich or 25 miles to Bury St Edmunds.

The study provides an overall local viewpoint of the health, social care, and wellbeing support of older people in the Debenham area.

3. Data collection

The researcher collected data about current services, and this was followed up with a survey via a questionnaire and focus groups with patients, service users and carers about these services.

For this project, the following data were collected:

- Data (2019-20) about Debenham, current services and the demography of the area
- Information from patients, service users and carers about current services via a
 questionnaire and a series of focus group.

4. Statistical Information and Data Analysis - Overview of the results (Highlights and Lowlights)

This overview seeks to paint a picture and broad analysis of the "numbers" involved in providing health, social and community care (and support) at the beginning of 2020 i.e. immediately before the pandemic. It is structured in terms of the various services that contribute to the support and wellbeing of those who are resident within and around Debenham.

This study has drawn on data from a wide range of organisations. We appreciate how difficult it can be to retrieve data in what is a very complex IT environment and are very grateful for all the assistance we have received. In a couple of cases, the data that we feel is important for a complete understanding of the contributions, activity, and costs directly involved in the provision of health care in Debenham and the surrounding area proved particularly difficult to access. However, we will continue to seek the data and update this report as and when we obtain it.

The following brief analysis and observations are based on the 2019-20 data detailed in (or can be accessed via) the relevant appendices to this report (Appendices 1-6).

General: The quantitative data seeks to describe the activity and cost involved in the key aspects of NHS, Local Authority, and Community provision of care for the elderly population of Debenham and the surrounding villages. Annually, the cost to the community is in excess of £16M (£1,800 per resident). Overall, the image is of a well-served community in terms of health care, and a strong level of community support. However, within that picture, inevitably, there will have been numbers of individual patients/clients (outliers) that may not have received the level of care they expected. This study was not designed to assess the level of these cases – other surveys are regularly conducted to measure patient

satisfaction/dissatisfaction with services. The picture in relation to social care, mental health and dementia does raise some significant questions.

Primary Health Care: The geographic community defined for the purposes of this study is primarily served by the Debenham Group GP Practice although there is an element of overlap with adjoining practices. It has a little less than 9,000 registered patients. 1 in 4 of these are over 65 years of age which is significantly greater than the Suffolk (20%) and national averages. Seventy (3.2%) of those over 65 have a diagnosis of dementia, also above the national average. However, purely in numerical terms, this figure probably substantially underestimates the actual incidence of the illness, certainly in its early stages, by perhaps 25%.

The GP surgery employs 10 senior clinicians (GPs and Nurse Practitioners) on a full and part-time basis equivalent to 6.5 full-time equivalent (FTE) consultants. Their average FTE GP caseload is approximately 1250 patients, or alternatively, 770 patients for each individual GP and equivalent nurse practitioner. They are supported by a further 31 (19.4 FTE) staff in a wide range of roles – clinical, administrative, clerical and management. Together they provide on average nearly 5,000 appointments per month. Of these, the over 65s, statistically, attend almost once a month whilst, for those under 65, it is less than half this figure. Only about 1 in 25 (4%) of patients do not attend their appointment.

The Place-Based Needs Assessment (2020) (Appendix 10) provides an extensive analysis of the local incidence of a wide range of illnesses and health conditions. Although there are some variations between GP practices, the situation within our area is broadly in line with that in the other practices throughout Northwest Suffolk, and close to the county and national averages.

Acute Health Care: As one might expect admissions to hospital represents the largest element of cost at £400 per day per patient. Over the year there were nearly 4,000 admissions for over 65s resident in Debenham and our adjoining postcodes, each with an average stay of 7.2 days i.e. 28,400 days. Statistically, on any one day 80 beds were occupied by patients living within the catchment. This resulted in a bill of £11.2M or £1,300 for each member of the population. 80% of admissions were as a result of attending Accident and Emergency (A&E) as an emergency. Every time someone over 65 it taken to A&E and admitted, it costs, on average, £3,000. Patients with dementia represent 17% of all over 65 admissions compared with a 3.2% incidence of dementia in the local population. On average over the year there were two older persons who were taken to A&E but not admitted, for every three members of the catchment population. The cost amounted to £0.9M or £150 per visit.

Social Care: Statutory social care and support is managed and delivered by the Adult Care Department of Suffolk County Council. It is responsible for arranging and funding domiciliary, day, residential, and nursing care at a cost of £4.7M (2019-20) which equated to about £550 per annum per person living within the area. 85 elderly persons were supported in their own homes at a cost of £1.4M, 96 were funded for their care in residential and nursing care settings at a cost of £3.3M, and only five were supported to attend day care sessions. Because there are no residential or nursing care establishments within the catchment i.e. not within 7-10 miles from Debenham, at the beginning of 2020 there were almost 100 older and frail persons who had had to leave their local community, friends and neighbours in order to

receive the care they need. The cost to Adult Care for residential care averaged £655 per week whilst it was £710 per week for nursing care. It should be born in mind that the average cost for privately funded care was substantially greater than these figures.

The figures for older and frail persons in residential or nursing care relates only to those who are receiving funding from the local authority and does not include those who have independently arranged privately funded care.

Of those receiving home care support 19% had a diagnosis of dementia. N.B. this does not include undiagnosed memory problems and other symptoms of the illness. However, the figure was 55% for those in residential/nursing accommodation.

Community Health Care: Community-based NHS care includes a variety of clinical support specialisms including physiotherapy, occupational therapy, etc. and is provided by either Suffolk Community Care Trust or Allied Care. To date we have not managed to obtain answers to the questions posed in Appendix 4 (mainly due to our being unable to find the right people to ask). We will continue the search and update the report in due course.

However, we do not believe that the lack of this data materially affects the overall picture.

Mental Health Care: The Norfolk and Suffolk NHS Foundation Trust (NSFT) is responsible for all mental health care services in the area covered by this research study. NSFT provides mental health care and support for about 2,200 over 65s living in Debenham and the surrounding area. By virtue of the current data collection system, it has proved difficult to analyse the statistics to the same degree as was possible for other care providers. Nevertheless, we can get a rough idea of the scale of NHS provision of mental health (MH) services to our older residents. Broadly, the number of patients over 65 within the catchment of the Debenham GP practice referred to the MH services was probably between 15 and 20, i.e. approaching 1% of the over 65 population. On average, outpatient appointments and home visits are consistent with this figure. We also see up to a 50% reduction of outpatient appointments, home visits, and emergency interventions between the years 2019 and 2020, possibly due to Covid-19 restrictions.

It is very clear that responding to dementia is the dominant feature of the provision of MH services to the elderly. The rate of diagnosis of dementia in new cases is averaging about 25 each year (1.25% of the over 65s) and there were about 150 interventions each year by the Dementia intensive Support Team to support current families living with the illness. It should also be recognised that 60% (90 out of 154) of those local elderly residents who are now being cared for in residential or nursing homes have dementia.

It is not really possible to evaluate the costs associated with the provision and response to the "probable" needs of the catchment area on the basis of the available data.

Local Support Groups and Social Activities: Debenham is fortunate to have a long history of community involvement in regard to the wellbeing of its older (and younger) population. Of particular importance are The Sports and Leisure Centre, the Churches, and The Debenham Project but there are other smaller groups that offer, perhaps, slightly less directed, but no less important, opportunities for residents to engage in activities that enhance their physical and mental wellbeing. Overall, the regular participation in activities and groups oriented

towards our older residents is estimated to be in excess of 1600 person sessions* per month (Sports and Leisure 900+; Debenham Project 220+; Faith groups 280+; other groups 180+).

Again, we have little data with which to evaluate the net cost of these services to the community. However, whilst the Leisure Centre is partly Local Authority funded, other community activities and groups are overwhelmingly self-financing.

Note: A person session is 1 individual participating in 1 group / session / activity or service on 1 occasion.

Information from patients, service users and carers about current services via a questionnaire and a series of focus groups

For this part of the study, ethical approval was sought and gained from the University of Suffolk Research Ethics Committee.

Inevitably, the user survey and focus group responses not only relate to the general (2019-20) provision of care, i.e. prior to Covid-19, but also to the period during the pandemic.

5.1 Questionnaire

A survey, in the form of a questionnaire was distributed via the Debenham Parish magazine and the Debenham project newsletter to people over the age of 65 living in the Debenham area. The questionnaire consisted of 16 statements to which participants indicated their agreement or disagreement using a Likert scale and then four further open-ended questions for participants to answer which provided opportunities for more detailed answers. The questionnaire was focussed on health and social care services in Debenham.

The numerical results of the questionnaire can be found in Appendix 7.

There were 15 responses to the questionnaire. The results from the statements with the Likert scale indicated agreement or strong agreement with 12 statements, where an average score of more than three indicates agreement, and more than four indicating strong agreement with the statement. There was disagreement with four statements, where the average score was less than three.

It is interesting to note that the four statements that indicated disagreement by the participants were all about social care services.

There was agreement that health services are good, participants were happy with who they can contact regarding health services, and they were happy with the GP practice.

Participants were less than satisfied with social services and the information that was available about social services in the area.

Participants generally felt well-supported to stay at home and manage their own health and social care needs. They were positive about not feeling isolated, about local social activities, local charities, friends and neighbours. Overall, they acknowledged that Debenham was a supportive community with 10 of the 15 participants strongly agreeing with this statement.

There were four open-ended questions at the end of the questionnaire which were;

- Do you have any examples of good health and social care services in the area?
- Do you have any examples of poor health and social care services in the area?

- Do you have any examples good or poor support that you have received from local voluntary groups or charities?
- Do you have any further comments or suggestions about services in the area?

The qualitative comments made in response to the four open-ended questions added the following themes and ideas from the participants.

GP surgery – there were examples given of good care from the GP surgery, although there were comments made about 'out of hours' GP services and how these were not nearly as good as the service provided during working hours.

Poor experiences of social care – several participants provided information about poor experiences of social care, both for themselves and others. Examples included waiting for a long time for referrals, a bit of a 'lottery' in quality-of-service dependent on the individual, not knowing which department to contact, being moved between services, confusion over who to contact and a lack of 'joined up' care.

Care for older people – it was felt by some of the participants that older people were not well catered for, and that they needed to have help in accessing services. For example, the move to online services has not been easy for older people if they do not have access to the internet or a smart phone and travelling to the hospital or other locations is not always easy. A better range of local services was needed for older people to access.

Community support – there was considerable praise for the supportive nature of the community in Debenham and for the Debenham project and other voluntary services and organisations in the village.

Out of hours services – participants raised this as an issue, stating that if anything happened outside of office hours, then access to both health and social care services was limited, and due to the rural setting, an ambulance took time to reach people in Debenham. It was suggested that a better out of hours service was needed.

Greater integration of health and social care services is needed – participants talked about services not 'talking to one another' and information not being shared between health and social care services. The participants suggested that a social worker could be allocated to the GP surgery to work alongside the GP practice.

Better support needed for people with Dementia and their families – this was mentioned by several participants who had experience of family members with Dementia. It was felt that there was very little statutory support, and that once the diagnosis of Dementia was given the person with Dementia and their family were left to seek their own support. The Dementia Together service provided by Sue Ryder was mentioned, along with The Debenham Project, but participants felt that more needed to be done to provide support.

5.2 Focus groups

Seven focus groups were held with a total of 16 participants during the months of September and October 2021. All focus groups were held face to face with Covid-19 measures in place. For each focus group a series of questions were posed to the participants, these questions can be found in Appendix 8. The focus groups were audio-recorded, and transcribed verbatim. The researcher reviewed the focus group transcripts and recordings and carried out a thematic analysis of the data from the focus groups.

There were four main themes that came from the focus groups.

- GP services
- Hospital services
- Social services
- Community and support services

For each of these themes, different sub-themes were discussed. These sub-themes are shown in Table 1.

Table 1 – Themes and sub-themes from the focus groups

<u> </u>					
GP services	Hospital services				
GP practice Online services Out of hours services Face-to-face appointments Having your own named GP	Travel and transport Quality of service				
Social services	Community and support services				
Poor experiences of social services Lottery system Care homes	Debenham project Supportive community Access to information Public health and education				

Each theme is now explored in detail using quotes from participants to provide illustrations.

5.3 GP services

In general, the participants were happy with the services provided by the GP practice. Examples were given of excellent care that they had received from either a GP or one of the staff members from the GP practice.

"I have been very impressed with um the...surgeries um...ability to get back to you quickly, and to be honest I have lived in a village not that far from here before so I have been part of the Otley surgery and have found likewise very good care, and I think from what I have heard from quite a few people in different areas that um feedback from surgeries is not always very prompt which OK can be for very good reasons, but does not actually help elderly people if they really want to be seen or even to be spoken with, so I think from that point of view I think you know it is very good" (FG3).

"I am registered here with the Debenham practice, they have always been really good at managing, because my husband had asthma checks and he had his regular reviews, so he was used to going there for that which was great" (FG4).

However, there were strong feelings from the participants about moving to online services. They felt that this was okay for people who were IT literate, had a computer or smartphone or had someone to help them, but for others the move to online services was a challenge.

"possibly some improvements in small areas...the basic concern I have is the push...to generally get everything online, because I think there are dangers in doing that, as you get older, if you get ill or you start to suffer, then going online is probably the last thing you want to do...and some people are not online...and so I understand why there is the push, but I think there needs to be a dual channel, online for those who can and want to, but there needs to be the personal touch for those who need it" (FG1).

"The doctor surgery [laughs] sent a letter to a 94-year-old I know, saying she had to get a mobile phone...as it was easier to them to contact her by mobile phone and send her a text message...excuse me! You know I just...it beggars belief" (FG2).

"When you want to get information that is quite challenging because most organisations would expect you to just look online" (FG7).

"I just want to add the concern I have about pushing everything online, I totally understand why that direction has been taken, but I do feel very strongly there needs to be a parallel, because not everybody can use online, nor is it always appropriate, I understand but I think that needs to be done proportionately" (FG1).

The participants felt that services during the week and between 9am and 5pm were generally good but seeking support from the out-of-hours GP service was not good.

"The GP practice is wonderful except when it comes to 12 o'clock on Friday when it shuts down to 8:30 on Monday" (FG1).

"We need local minor injury clinics for the weekend." (FG7).

During the Covid-19 pandemic the GP surgery, like all GP surgeries offered online or telephone appointments. The participants were grateful that the GP service continued, but they agreed that there was no substitute for a face-to-face appointment with one participant giving an example of a rash and being asked to take a photograph, which she refused to do due to the location of the rash.

"Well, I think there is an interesting point in there about telephones, because there is no substitute for a face-to-face consultation, I realise there were measures put in place, but I realise that makes things very challenging for people. I was asked to take a photo of my rash and send it in, not appropriate due to its location" (FG6).

"I do know that there are a number of surgeries around here and in Essex where doctors are seeing patients face to face, and ours are not, so...so I um...I guess I find it very frustrating, telephone conversation you cannot get the message across in a telephone conversation" (FG2).

"I think we need to be able to see our GPs and we need to be able to check in" (FG7).

It was felt by some of the participants that there was now a lack of personalised service from the GP practice. They spoke about a time when they had their own 'named' GP, and that GP would get to know their patients. They felt that this was a real help, especially as an older person, as the GP would get to know them better and provide a more personalised service.

"...and I had a long interview with a doctor who I thought was my Doctor, and um...sometime later on, I think I was transferred to another doctor whose name I cannot remember, but I felt I had a doctor who knew me and I knew, but now it seems to be completely normalised, I had to fill out a form at Ipswich hospital for something or other, and I had to fill in name of doctors, and I did not know what to put down, all I put down was the name of the surgery" (FG1).

"I do have a named doctor but it depends whether she is on call, or that day in the surgery, so when you ring up what happens is they say oh you can see Dr so and so at such and such a time and I say well ok I cannot do that day oh well Dr so and so is on, but it is not necessarily my doctor and stuff, which is fair enough I guess as they have the same notes, but I do not know if it is a different person whether they would know much about you as they have so many patients and such" (FG1)

5.4 Hospital services

Participants were positive about the health services they had received at the hospitals they had attended.

"I had had my irises lasered at Ipswich hospital, and that is fantastic, and apparently the optician had picked up on it really quickly, and the follow up on that continues to be really good actually, when I get called in to keep an eye on this situation" (FG3).

"Yes, my son, many years ago he had as asthma attack, and he was seen immediately by someone in hospital...and he had an accident some years ago which led to other problems, and his health care has been amazing" (FG3).

However, transport to and from hospital was an issue from Debenham. Although there are buses, these take time and there is no direct bus service to either Ipswich or West Suffolk hospital from Debenham. If you can drive, then this is not too much of an issue, however if you cannot drive you either go by bus or hospital transport, or you rely on friends, neighbours or relatives. The Debenham project have volunteer drivers who can take people

"It is difficult to get to the hospital, at the moment you drive, but if you had an appointment at Ipswich or West Suffolk Hospital. That is easier to access because you can go there by bus. Two buses...to Ipswich Hospital...and then it is quite a walk, the bus does not go into the hospital" (FG6).

"I mean we could not be in a worse situation in Mid Suffolk...and there are not that many communities which are that isolated...we are between hospitals...yes I think a lot of...transportation is appalling" (FG7).

5.5 Social services

The feedback about social services was not as positive, some participants reported good experiences.

However, the majority of the feedback about social services was not as positive as it was about health care services. Social services were described as a 'lottery system' where it largely depended on the member of staff that you first had dealings with as to how your experience went.

"I had to do quite a lot of digging and I started off with Age Concern, Age UK, and they put me in touch with various people, and then the occupational therapy people put me in touch with somebody else, and it is all put you in touch with somebody else, and it is delegated out because the Council no longer do this particular thing any more, and then they decided to change that and bring it back in house again, and it is a bit of a challenge" (FG2).

"It is very frustrating, so social care, so I believe Meadows in Framlingham is a very good quality care home, but throughout social care it is not consistent, and some of the things you hear are shocking, so I think you know" (FG3).

"I would not say social care in the home has got better, and there are all sorts of reasons for that, recruitment, lack of team, communication, resources, and I think it is a shocking, shameful scandal in our country, as these are the most vulnerable people, so I really hope we do not need social care in the future, and I hope it will have improved" (FG3).

"...it depends on which individual you come across as to how good or bad the service is, when we were in a crisis situation things were sorted quickly, but when it was, not run of the mill, but normal, there was no emergency or quick dealings" (FG4).

One participant suggested that a single point of contact in social services would be helpful.

"So ideally what you want is a single point of contact and someone who says ok I can do this or I cannot but I know someone who can and they get back to you. You want to deal with the same person all the time, you want them to feed in slowly the things you need or might need, to say this is available but at the moment you do not need it, this is what may happen down the road, and if this happens this is how we will cope with it...and I think somebody who you have formed a relationship with who can say to you I think this might help" (FG4).

Participants also discussed care homes and felt that these came under the auspices of social care. There is no care home in Debenham, and so anyone who needs to move to a care home has to move outside the village which makes visiting people in the care home challenging for family members, especially if they do not have their own transport.

The participants made some suggestions about how health and social services could work together.

"The social care side just steps back away from it and it just by default ends up you know as the GPs door when it is much larger problem than just the health side...a holistic approach...and that is you know, that is health and social care working together in the community at the work face, not at you know the organisational level..." (FG4).

5.6 Community and support services

The participants were full of praise for the Debenham project and for the volunteers who run the project. The project is aimed at people with dementia and their families, however the activities and volunteer services that they run are not exclusive to this group of service users, and all members of the community are welcome.

"I think the Debenham Project is a wonderful institution, I do not make very full use of it myself, I go to keep fit and um...what else, lunch group" (FG1).

"when I was a carer of my late husband um I mean it was not a very long period but the idea of being able to come and somebody else to take over while you go shopping or something as carer I think is a wonderful, you know because it can be such a you know, being along at home with somebody with dementia...well...[sighs] it drives me mad" (FG1).

It was agreed that Debenham is a very supportive community, this was demonstrated during the Covid-19 pandemic where friends and neighbours supported the older population. However, participants assured me that Debenham is a good place to live and that everyone is friendly and supportive. They all felt well-supported by friends and neighbours.

"I think we are definitely blessed with a very supportive community in general, not just charity, but quite a lot of good neighbouring going on....during COVID we had a group, which I set up, to get shopping or presentations for people in isolation, and people made friends from that, and it has expanded community support across the board which is good to see" (FG1).

They did speak about how they accessed information, the newsletter was mentioned, and there was also a discussion about how a lot of information is online and how prohibitive this is, this was discussed earlier in relation to health and social care services.

"we get the Debenham magazine now, you know the Church magazine, and that has got a lot of good information in it, but not everybody gets that, now what I know of Debenham and what I have seen of Debenham, we do walk up the street and people will say hello even if we have never met them" (FG2).

Finally, some of the participants in focus group 3 discussed public health and education, they felt that there needed to be better education of the public about healthcare issues and that this would help with the use and uptake of health and social services.

"I feel that although we are living longer, we are not living healthier, and so the need for services is so great, probably us older people are the healthiest in a sense, for the lifestyles we are living in society, young people may have a greater need than us, because of pollution, lack of nutritional awareness, lack of dental care...so yes the sooner they actually, and they probably, the amount of money that is needed to address social care is very small because of the numbers of people involved, I believe when people go to care homes they live maybe two years, so really it is such a small amount of money, and it would save an awful lot from people not needing to go to hospital...if you do not need an operation or transfusion you do not need to be in hospital do you, I mean even medication that needs to be given as...does not have to be administered in hospital, and only if initiative to be taken to keep people out of hospital, the money that would be saved long term" (FG3).

"if they had spent as much money on health education as they did on computers and technology then we would have a very different world, more empowered young people when it comes to contraception and sexuality, and a lot of problems that are happening to do with young people and computers and social media, maybe we would have a different culture around that, and drugs education, maybe it is a lack of vision, it would be lovely to see schools sit down and eat together, first lesson is a free school meal, pastoral care that would make a difference with nutrition, and I think it is a lack of vision of joining up education and where you are going to be one day in your life, it is sad, as I say the expertise is there, but it is not joined up and the priorities seem to be very much to do with market forces...on the high street why more fast food shops, why not more cafes?"(FG3).

"I think there is a need for educating people to eat properly as well because there is no two ways about it, it is very worrying thing there is so much diabetes in this country...I believe it is 1 in 10 or something, and increasing, now you have to ask yourself why is that, and the answer is that they are not eating the correct things, and they are also not exercising either, and there is far too much prevalence at looking at your iPad rather than going out for a good old cycle ride or walk as we did when we were children, or wholesome food, and to me it is worrying that there is so much obesity...heart attacks um and you know if we are going to live longer we have got to live healthier, for our own benefit, but also that we are not actually having to access the services there, because we are costing the country a massive amount of money, and I think that level of education cuts through" (FG3).

6. Conclusion

The data collected during this project about Debenham, current services and the demography of the area along with the information from patients, service users and carers about current services via a questionnaire and a series of focus groups has provided an overview of health and social care services in Debenham and the surrounding area.

The study provides an overall local viewpoint of the health, care, and wellbeing of older people in the Debenham area.

It is clear from the data that there is a supportive community and that residents provide support for one another. The Debenham Project is well-known and held in high regard amongst the residents. The project provides help and support for people with dementia and their families, and also help and support for anyone who requires help and support with health and social care needs.

In general, the feedback about healthcare and the GP practice was positive. Participants were concerned about out of hours provision and transport to and from hospital. However, they were satisfied with the quality of care that they had received.

The feedback about social care was mixed, although there were few positive experiences recorded. The participants noted that there was a lack of 'joined up' thinking and that services varied depending on the individual that you dealt with.

There were a number of suggestions from the participants about how health and social care could work better together including the deployment of a social worker to be based at the GP practice.

This study has highlighted that people over the age of 65 should be consulted about health and social care, as they have an excellent insight and worthwhile suggestions, but feel that their voices are not always heard.

7. Postscript by Lynden Jackson (Chair of the Debenham Project)

If you have got this far you will be wondering what the next steps are; how will the contents of this report be disseminated and to whom; why might they take notice, and where will it lead. Primarily, this is the first step in a way to view the statistical and anecdotal data on an integrated community basis, and to make it accessible, understandable and relevant to the people who use (and pay for!) our local health, social, and community care services. The cost of these services is very substantial. So, local involvement and debate in their future provision would seem to be a natural desire. We believe that this report offers the evidence necessary for such a debate.

Initially the report is being distributed to key stakeholders and providers e.g. the GP Practice Social Services, the Parish and District Councils, the Mental Health and Community Health NHS trusts, asking for comments that can be included as an addendum.

Clearly, there are areas where there are gaps in the data. These we shall seek to fill.

Other suggestions considered for following up on the study are:

The report contains a great deal of local data. Some features have been drawn out, but further analysis will be explored and, particularly, comparisons with the National and County pictures.

Work with the Parish Council to explore the potential for a local Health and Social Care Development Plan and consider updating the data on a regular basis.

Propose to the Suffolk Health and Wellbeing Board for it to become a model for other communities.

Seek professional publication of the research.

Clearly, the Government and the Local Authorities must tackle the systemic difficulties that exist in both the NHS and Social Care. I hope that they will take note of this research which strongly identifies the importance of involving local communities in deciding the future of the NHS and Social Care.

8. Acknowledgements

The author and The Debenham Project wish to recognise the contributions of all the organisations who have provided the statistical data upon which this report is based, the residents of Debenham and the surrounding villages who took part in the survey and the focus groups, Debenham PCC for its support, and all those who have encouraged and advised us. We are so grateful – Thank You.

9. References

Office for National Statistics (ONS) (2011) *Civil Parish Population - Neighbourhood Statistics*. Retrieved 19 August 2016

Delaney T & Matthews A (Public Health Suffolk); "A Place-Based Needs Assessment"; North West (Suffolk) Integrated Team; V2 2020

"The Debenham Project (Dementia – Caring for the Carers)"; Registered Charity (No. 1133501); http://www.the-debenham-project.org.uk/

Appendix 1: Primary Care

The GP surgery in Debenham is part of The Debenham Group Practice. The Debenham Group Practice has GP surgeries in Debenham, Otley and Grundisburgh and covers a large rural area. The postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 are all in the catchment area for the GP practice group.

1. Demography: As at 01/01/20 the number of patients registered at the GP practice group was 8,842, with 4,368 male and 4,474 female patients. The numbers of patients in each age group at 01/01/20 can be seen in Table 2 below.

Table 2 – Debenham Group Practice Patient Demographics

Age	Male	Female
0-4	159	154
5-14	498	526
15-44	1211	1206
45-64	1413	1472
65-74	645	635
75-84	347	338
85 and over	95	143
Total	4368	4474

In addition, the following data were also collected:

- Patients over 65 registered at the practice = 2,203
- Over 65s with Dementia = 70, this is 3.2% of the patients over the age of 65 that are registered at the practice
- There are also three patients with Dementia who are under the age of 65 registered at the practice

Staffing at the Practice & services provided

Table 3 – Staffing at the Practice as at 01/01/20

Job Role	Number in Post	Full Time Equivalent
Administration	5	2.9
Advanced Nurse Practitioner	1	0.8
Cleaner	2	0.6
Dispenser	9	5.8
GP Partner	4	2.6
Health Care Assistant	3	1.8
Management	1	1

Medical Secretary	2	1.1
Nurse Practitioner	2	1.2
Pharmacist	1	0.2
Practice Nurse	2	1.6
Receptionist/Care Navigator	6	5
Salaried GP	3	1.9
Total	41	26.5

- Total number of clinical appointments at the practice in an average month
 - o Patients over 65 = 2035
 - o Patients under 65 = 2950
- Did not attend (DNA) in the same period
 - o Patients over 65 = 65
 - o Patients under 65 = 112

Appendix 2: Hospital Care for patients within IP6, IP13, IP14 and IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 postcodes in the 2019/20 financial year

Emergency Admissions

Table 4 – All patients			
Admission Method	Activity	Total LOS	Total Cost
Total	3,954	28,527	£11,237,855
a. Number of admissions for over 65s	3,954		
b. Average length of stay for over 65s	7.2		
c. Average cost per day for over 65s	£393.94		
d. Number of admissions via Accident & Emergency (A&E) for over 65s	3,215		
e. Average cost of admission via A&E for over 65s	£2,847.36		

Table 5 – Patients with Dementia			
Admission Method	Activity	Total LOS	Total Cost
Total	658	5,465	£ 1,984,829
f. Number of admissions for over 65s - with dementia	658		
g. Average length of stay for over 65s - with dementia	8.3		
h. Average cost per day for over 65s - with dementia	£363.19		
i. Number of admissions via A&E for over 65s - with dementia	599		
j. Average cost of admission via A&E for over 65s - with			
dementia	£2,972.04		

A&E attendances from patients

Table 6 – A&E Attendances

a. Number of attendances for over 65s	6,042
b. Average cost per attendance for over 65s	£148.00
	1

Appendix 3: Adult Care Services for clients in the postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 as at 01/01/2020

Table 7 - Number of people receiving social care at home, different types of social care; domiciliary, very sheltered and high dependency

Current Customers

Customers in the Last 12 Months

Dementia Indicator	Unique Customer Count	Average Weekly Cost	Dementia Indicator	Unique Customer Count	Average Weekly Cost
N	69	298.52	N	88	272.82
Υ	16	439.23	Υ	23	222.48
Total	85	325.01	Total	111	262.15

Table 8 - Number of people receiving care in nursing homes whose previous address was within the Selected Postcodes.

Current Customers

Customers in the Last 12 Months

Dementia Indicator	Unique Customer Count	Average Weekly Cost	Dementia Indicator	Unique Customer Count	Average Weekly Cost
N	14	634.52	N	20	627.12
Υ	17	773.19	Υ	29	778.94
Total	31	710.57	Total	49	715.55

Table 9 - Number of people receiving care in Residential homes whose previous address was within the Selected Postcodes:

Current Customers

Customers in the Last 12 Months

Dementia Indicator	Unique Customer Count	Average Weekly Cost	Dementia Indicator	Unique Customer Count	Average Weekly Cost
N	29	659.48	N	44	662.24
Υ	36	652.77	Υ	61	659.42
Total	65	655.76	Total	105	660.53

Table 10 - Number of people receiving day care services

Current Customers

Customers in the Last 12 Months

Dementia Indicator	Unique Customer Count	Average Weekly Cost
N	3	71.24
Υ	2	99.15
Total	5	82.41

Dementia Indicator	Unique Customer Count	Average Weekly Cost
N	5	74.90
Υ	2	92.27
Total	7	81.29

Appendix 4: Community Health Care data for patients in postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 as at 01/01/2020

Finding the key person who can provide this data has proved surprisingly difficult. We will continue to seek the statistics we asked for and update the report when they become available.

Catchment population Total

Budget

Number (FTE*) of Front-line Professional Staff

REACT

Number of Patients (over 65)

No. of Appointments

Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE*) of Front-line Professional Staff

Admission Prevention

Number of Patients (over 65)

No. of Appointments

Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE*) of Front-line Professional Staff

Early Intervention

Number of Patients (over 65) No. of Appointments Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE*) of Front-line Professional Staff

District Nursing

Number of Patients (over 65)

No. of Appointments

Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE*) of Nurses

Community Matrons**

Number of Patients (over65) No. of Appointments Total

Cost

Number of Patients (with dementia) No. of Appointments Total

cost

Number (FTE*) of Matrons

Community Therapy (Physio)

Number of Patients (over65) No. of Appointments Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE*) of Front-line Professional Staff

Community Therapy (OT)

Number of Patients (over65) No. of Appointments Total

Cost

Number of Patients (with dementia)

No. of Appointments

Total

cost

Number (FTE) of Front-line Professional Staff

Other services

Number of Patients (over65) No. of Appointments Total

Cost

Number of Patients (with dementia) No. of Appointments Total

cost

Number (FTE) of Front-line Professional Staff

^{*} Full time equivalent

^{**} Not sure if this is the same a District Nurses

Appendix 5: Mental Health Care data for patients in the postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 as at 01/01/2020

This dataset provides figures for the level of activity but evidence of the cost to the community continues to prove difficult to obtain. We will keep trying to find the statistics and update the report.

Norfolk and Suffolk Mental Health Trust

N.B. The data in this table has been provide by NSFT for a wider population than Debenham and the surrounding villages

We have normalised the data to provide an estimate of the numbers for our local community.

Ipswich & East Suffolk CCG

Total Population	76095
NSFT Cohort Population (Postcodes + over 65)	5323
Debenham GP Practice catchment population (over 65)	2200

Dementia

Domonia	Cohort Dat	a	Debenham (Normalise	
	2019	2020	2019	2020
Patients	42	33	17	14
Referrals	90	80	37	33

	Average/Unit cost						
MH Consultant Appointments	?	?	?	?	?		
Memory Assessments	60	58	25	24	?		
DIST Interventions	425	329	176	136	?		
Emergency Interventions	57	36	24	15	?		
Care Support Package	?	?	?	?	?		
Outpatient Appointments	48	23	20	10	?		
CPN visits	106	44	44	18	?		
Inpatient episodes	0	2	0	1	?		

Appendix 6: Local Support Groups and Activities data for the postcodes IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7 as at 01/01/2020

This table identifies most of the community groups that were known to be active prior to the Covid-19 Pandemic.

Activity/Service		Frequency	Membershi
Carers Club and Info			
Cafe	DP	Fortnightly	30 - 40
Fit Club	DP	Weekly	15 - 20
CAMEO	DP	Fortnightly	15 - 20
One to One	DP	On request	4 - 6
Transport	DP	On request	20 - 25 per ı
Lunch Club 1	DP	Monthly	6 - 9
Lunch Club 2	DP	Monthly	7 -9
Lunch Club 3	DP	Monthly	15 - 18
Gentle Aerobics	DSL	Weekly	20
Walking Netball	DSL	Weekly	20
Badminton	DSL	Weekly	21
Dischord Choir	DSL	Weekly	30-40
Carpet Bowls	DSL	Twice weekly	10
Indoor Kurling	DSL	Twice weekly	8
Traditional Music Scottish Country	DSL	Monthly	25-35
Dancing	DSL	Weekly (Sep - May)	20
Bridge Club	DSL	Weekly	8
Lunch Club	DSL	Fortnightly	15-20
Mobility	DSL	Weekly	10
Cream tea	DSL	Fortnightly	4
Zumba Gold	DSL	Weekly	15+
Friday Fun	DSL	Weekly	0
Country Music	DSL	Monthly	100+
Mens' Shed	TF	Weekly	15 -20
Womens Institute	С	Monthly	20+
Knit and Natter	С		6 - 10
History Society	С	Monthly	20-25
Past Times	С		
T+	С	Weekly	30 - 40
Lunch Club	F (Forge)	Monthly	15+
Pop-In Coffee Morning Sunday Church	F (CoE)	Weekly	8+
services CoE social events CoE Soup Lunch Sunday Church	F (CoE)	Weekly	40 - 50
services		Weekly	20+
URC events	F (URC)	2 or 3 per annum	40-50

Key: Debenham Sports & Leisure Centre; Debenham Project; Two Fields; Coopersfield; Faith.

Appendix 7: Questionnaire results

Respondents: 15

		Strongly disagree	1	2	3	4	5	Strongly agree	Average score
1.	As someone over the age of 65 living in the Debenham Area, I am satisfied with Health Services in my area.				6	9			3.6
2.	I know which services to contact if I have a healthcare need.			1	4	7	3		3.8
	I am happy with the information I have available about health care services in the local area.			1	5	9			3.53
4.	My General Practitioner (GP) Surgery provides all the usual healthcare services that I need.				3	9	3		4
5.	My GP surgery will refer or signpost me, to a hospital or a specialist consultant doctor and/or other healthcare services if I need them.				2	6	7		4.33
6.	As someone over the age of 65 living in the Debenham Area, I am satisfied with Social Care Services in my area.		3	6	5	1			2.27
7.	I have used Social Care Services and knew which services to contact.		1	3	2	3			2.78
8.	I have not ever needed Social Care but would know which services to contact if I did.		2	2			2		2.67
9.	I am happy with the information I have available about social		5	5	1	3	1		2.33

care services in the local area.						
10. I feel well supported to stay at home.	1		4	4	6	3.93
11. I am able to manage my own health and social care needs with the help and services available to me.		1	4	5	5	3.93
12. I do not feel isolated.	1	1	1	6	6	4
13. I am aware of local voluntary groups and charities that can help me if I need them		1		6	8	3.87
14. There are social activities which I am able to join in with.	1		1	6	7	3.67
15. I have friends and neighbours that I can call on if needed.	1			6	8	4.33
16. Debenham is a supportive community.				5	10	4.67

Appendix 8: Focus Group Questions

- 1. Discuss what you think about the Health and Social Care Services in the area.
- 2. Is information readily available about services?
- 3. Tell me about the GP practice?
- 4. Do you feel supported to stay at home and manage your health and social care needs?
- 5. Do you feel isolated or are there social activities you can join in with?
- 6. Do you have any examples of support that you have received from local voluntary groups or charities?
- 7. What about friends and neighbours?
- 8. Do you have any examples of good health and social care services in the area?
- 9. Do you have any examples of poor health and social care services in the area?
- 10. Do you have any further comments or suggestions about services in the area?

Appendix 9: Anonymous verbatim transcriptions of focus groups and interviews.

All interviews and focus/discussion groups were recorded with the permission of those involved, and then transcribed and anonymised.

These records are available on The Debenham Project website at:

https://the-debenham-project.org.uk/downloads/researchprojectuos/FocusGroups.pdf.

Appendix 10: Place-Based Needs Assessment for Eye/Northwest Suffolk in 2017 - 19.

Produced by Public Health Suffolk, this is a very comprehensive data analysis of the key factors contributing to health, social and wellbeing in the rural area containing the communities of Eye, Fressingfield, Debenham, Claydon, and Stowupland. The total population is approximately 39,000. The report contains an assessment of the demography, population, housing, deprivation, health conditions, hospital admissions, adult care needs, children health, older persons' wellbeing, etc.

Delaney T & Matthews A (Public Health Suffolk); "A Place-Based Needs Assessment"; North West (Suffolk) Integrated Team; V2 2020; https://www.healthysuffolk.org.uk/uploads/Eye North west INT PBNA v2.pdf

Appendix 11: Statistical considerations

Representativeness: This study was designed to obtain data which is statistically representative of a typical rural community. In this case, the large village of Debenham and the surrounding small villages within a radius of approximately four miles. This catchment contains a population of roughly 6,500. Alternatively, the Debenham Project has used the area that the local GP practice serves. The current number of patients registered with the practice is 8,842. Unfortunately, Social Care data is collected in relation to the catchments of the Integrated Network Teams (INTs) which are much larger and do not easily map onto NHS data. However, most data can be sorted and selected by postcode. When we filter using the Debenham (IP14 6) postcode and adjoining postcodes, this catchment contains a population of about 8,600. We concluded that by using a combination of postcode and GP practice derived data we could confidently argue that the statistics are statistically representative of the community.

Covid-19 impact data mitigation: As mentioned, the initiation of the study pre-dated the Covid-19 pandemic. However, the collection of statistical data was already underway at the beginning of 2020 based upon figures for 2018-19 and 2019-20. In reality this has excluded any data post March 2020 i.e. between the beginning of the

pandemic and the present. Since this period has been one of almost total disruption of normal practice, current local statistics are unlikely to represent more than an insight on the impact of the crisis. We believe that, in time, the situation will tend towards resuming a historical normality, and the results of the study represent the underlying situation.

Significance: With regard to the significance of the data and their subsequent analysis, the size of the overall population of the community is a critical parameter. If it is too large the results will tend towards the county/regional levels. If it is too small the numbers lose their statistical significance when compared with other communities and/or national data. We believe that a statistical population of between 5,000 and 10,000 represents a practical compromise which allows confidence in our analysis of the data. Nevertheless, derived figures of less than 50 should be treated as subject to significant error margins and considered only as guidance.

In our case, for the collection of data, the overall population of circa 8,500 is well defined in geographical terms by the postcodes (IP6 9, IP13 6, IP13 7, IP14 5, IP14 6, IP23 7) and in nature as a central large rural village together with a number of surrounding smaller villages. It is uniformly rural and not overlapping with any urban communities. It is also defined by the area served by the Debenham GP Practice which is the dominant provider of primary care health services. However, there are a number of patients living within the catchment who are not registered with this practice. Also, there are a number of patients who live outside the area who are registered with the practice. Nevertheless, in percentage terms these numbers are small, and we consider them to broadly balance each other out.

However, there are significant demographic differences between Debenham's population and those of the more outlying villages due to its central location, housing availability, presence of schools, sports facilities, shops, businesses, etc. Thus, seeking, by scaling, to deduce data for specific locations within the catchment e.g. Debenham should be treated with caution. In addition, any such derived statistic may have significant margins of error due to the sampling process – the smaller the number, the higher the potential for error.

Consequently, we have concluded that it is reasonable to assume that the data and resulting conclusions are a good reflection of the area.

Accuracy: Every effort has been made to obtain accurate data and data as up-to-date and as relevant as possible. We are very grateful for all the help we have received. Inevitably, it has not been possible to fulfil all the requests for statistics we have made but we believe that which we have received has enabled a fair picture to be presented.

Completeness: It is inevitable that a research project such as this cannot provide total information about everything in a community that contributes to the support of its elderly frail members. There are some elements that have been difficult to evaluate, e.g. care agencies, and independent domiciliary care providers. There are some providers of services which have had, for various reasons, had difficulty in meeting all of our requests for data e.g. mental health and community healthcare. Also, the operating costs of the Debenham GP practices have not been included. Finally, the level of privately funded residential care charges and, especially, the commitment of informal family carers who devote a huge amount of their quality of life to their loved ones, are very significant "hidden" costs in the equation.