

The Enriched Opportunities Programme:

A cluster randomised controlled trial of a new approach to living with dementia and other mental health issues in ExtraCare housing schemes and villages.



Published in 2009

Published by:

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All names of care facilities, residents, tenants, family members and staff have been anonymised for the purposes of this report.

We gratefully acknowledge the cooperation of all the above in the commitment they showed in helping bring this piece of work to fruition.

We would like to thank all the donors who made this research possible through their kind support of the project. These include:

**The Forte Charitable Trust
The Freemasons' Grand Charity
Garfield Weston Foundation
The Mercers' Company
The Pilkington Charities Fund
Reuben Foundation
The Henry Smith Charity
The John & Margaret Wootton Charitable Trust**

and many others - some of whom wish to remain anonymous.

This report was prepared by Professor Dawn Brooker, Dr Elaine Argyle, Mr David Clancy and Mr Andy Scally as part of a commissioned piece of research to evaluate the impact of the Enriched Opportunities Programme.

Steering Group members, chaired by Mr Jeremy Porteus and senior staff at the ExtraCare Charitable Trust contributed greatly to its preparation. Particular contributions were made by Mr Guy Page, Mr Steve Burnell and Mr David Campey.

There are many more people we could mention who made this programme possible but without the dedication and hard work of our Locksmiths and Project Support Worker Coaches we could not have achieved the outcomes that we did. We particularly thank Spencer Crowe, Balbeir Gill, April Harper, Patricia Hayward, Mike Hill, Norma Mather, Annette Platek, Joanne Taylor and Kate Trevis.

Summary

People living in extra care housing have a variety of mental health needs. Whilst many people opt for extra care housing as a means of enhancing quality of life, it is recognised that around 30% will experience significant mental health problems notably dementia and depression. This often leads to them having to move out of extra care housing or becoming isolated within their apartment.

The Enriched Opportunities Programme (EOP) was developed by ExtraCare Charitable Trust and Professor Brooker and her research team as a means of ensuring that people experiencing mental health problems can continue to enjoy a good quality of life. EOP brings together what is known as best practice in a structured, systematic and proactive way. Key facets of the programs include a specialist staff role “the EOP Locksmith”; staff training; individualized case work; liaison with health and social care teams; activity & occupation; and leadership.

This report summarises a recently completed 2 year cluster randomised controlled trial.

5 extra care housing schemes were randomly assigned to receive the EOP for an 18 month period. A further 5 housing schemes were randomly assigned to receive a placebo intervention consisting of employing an extra member of staff called a Project Support Worker Coach (PSWC) for the same time period.

We followed the lives of the 268 most vulnerable residents living in all these extra care housing schemes and villages. We compared the results for people receiving the EOP intervention with the PSWC intervention and analysed the differences.

The process of implementing EOP and the impact on people’s lives has been very positive. The main advantages in the EOP schemes were that residents were

- Half as likely to have to move out into a care home
- Far less likely to spend time in hospital as an in-patient
- More likely to have a GP visit
- More likely to see a community physiotherapist, occupational therapist and a chiroprapist

- More likely to have their mental health problems diagnosed

In addition residents in the EOP schemes and villages

- Rated their Quality of Life more positively
- Reported decreased symptoms of depression over time
- Reported greater feelings of social support and inclusion

There were also a number of advantages enjoyed by participants in both the EOP and the PSWC interventions. Residents in both interventions reported

- Greater opportunity to be active
- Greater use of community facilities
- More fun
- Greater variety of things to do

This report will be of interest to all those involved in the provision of extra care housing and to those implementing the National Dementia Strategy.

Part 1: The Enriched Opportunities Programme, its development and the methods used in the current study

Key personnel from the ExtraCare Charitable Trust and Professor Dawn Brooker have been working together since 1998 to find ways of improving the quality of life for people living with dementia. The starting point for the development of the Enriched Opportunities Programme followed on from the experience of taking a group of ExtraCare nursing home residents with dementia on an Activity Challenge week where people experienced canoeing, abseiling, swimming, hot-air ballooning and a host of other exciting activities. The levels of well-being that people showed on these short breaks staggered us (Brooker, 2001). Once back in the nursing home setting, however, levels of well-being reverted back to “normal”. This spurred us on to see whether it was possible to really improve quality of life as part of regular care home routine.

The Enriched Opportunities Programme was developed to address this. A three-way forum for discussion and action was established between the research team, the practitioners (key operational staff) and family carers in the four practice development sites, and a group of thirty experts from a variety of research, professional, therapy and training perspectives in dementia care.

Collectively this forum was known as the Expert Working Group. All members brought their expertise to the group in order to shape the Enriched Opportunities Programme from a theoretical ideal into a usable intervention within long-term care.

The Expert Working Group met initially for a two-day meeting. The recordings of presentations and ensuing discussions of this first meeting were transcribed to help guide the project (Brooker and Woolley, 2003). A further five EWG meetings were held in this advisory capacity over the course of the evaluation. All meetings were recorded and notes made for analysis. Between times, individual members of the Expert Working Group provided training and mentorship.

A key factor in the development of the Enriched Opportunities Programme was trying it out in real-life situations in a controlled manner and having on-going feedback from the practice development sites and learning from them. The Enriched Opportunities Programme was implemented consecutively in the four practice development sites with one or more months' gap between the start of each. This meant that expertise and practical implementation techniques could be developed from each scheme and shared between them. These practice development sites included three dementia specialist nursing homes and one extra care housing scheme.

The published literature was reviewed at the beginning and throughout the development of the programme to develop the research evidence base for the different elements of Enriched Opportunities Programme (Brooker & Woolley, 2007).

We undertook in-depth case studies in the extra care housing scheme and a quantitative analysis of the impact across three dementia specialist nursing homes (Brooker, Woolley and Lee, 2007). A repeated measures within-subjects design was employed, collecting quantitative and qualitative data at three points over a twelve-month period in each facility with follow-up 7 to 14 months later. 2-way ANOVAs revealed a statistically significant increase in levels of observed well-being and in diversity of activity following the intervention. Participants benefited regardless of level of dependency, diagnosis or level of cognitive impairment. There was a statistically significant increase in the number of positive staff interactions with residents. There was a significant

reduction in levels of depression. The EOP demonstrated a positive impact on the lives of people with dementia in nursing homes already offering a relatively good standard of care, in a short period of time.

ExtraCare housing

The provision of extra care housing is increasingly put forward as a means of improving the quality of life of those individuals requiring support while maintaining their independence and rights of tenancy or home ownership (Royal Commission on Long Term Care, 1999; Department of Health, 2005). Within this policy emphasis, it is envisaged that mainstream planning and provision of extra care housing schemes will be inclusive of people with dementia, older people with learning disabilities and those needing intermediate care. The emphasis of this policy on social inclusion and participation, wellbeing and the enjoyment of active ageing sits well with current literature on promoting quality of life for older people and those who live with dementia or other mental health problems.

A range of information on providing extra care housing to people with dementia can be accessed through the Housing Learning and Improvement Network website (Department of Health, 2009).

People living in extra care housing have a variety of mental health needs. Whilst many people opt for extra care housing as a means of enhancing quality of life, it is likely that some people will experience significant mental health problems. Some may have long-standing mental health problems that they have experienced throughout their lives and which re-emerge in later life. Others may go on to develop problems whilst they are living in extra care housing. Sometimes these problems may be triggered by social and physical losses. Sometimes they may be a result of neurological disorders such as dementias or stroke.

A preliminary survey of the 10 housing schemes involved in the research reported here indicated that residents experienced significant problems associated with dementia and depression (Brooker, Argyle & Clancy, 2009). Staff teams in extra care housing are able to recognise that people are at risk but do not readily express this in diagnostic category terms or recognise the need to gain diagnosis and treatment for mental health issues.

Without proactive strategies in place, it is difficult to assess in the longer term what will happen to people who develop significant cognitive disabilities or other mental health problems within extra care housing.

As is the case with community-dwelling individuals, it could be that the sense of belonging that living in an extra care scheme could enhance feelings of wellbeing and mental health (Bailey and McLaren, 2005). On the other hand, the stigmatisation of people with dementia (Werner, 2005) or people with mental illness (Depla et al, 2005) might create a barrier to quality of life.

Anecdotally, people with dementia and other mental health needs have been observed to become isolated and stigmatised in schemes that are primarily set up to benefit older people with physical frailties. However, this area of research is under-investigated in extra care housing.

The only UK longitudinal study looking at how people with dementia fared in extra care housing over a three-year period showed that residents with dementia and their relatives were very positive about extra care as an experience (Valleley et al, 2006). However, over half the people with dementia they followed were admitted to other care settings during the first two years. Reasons for moving on were given as challenging behaviour, conflicts with staff and other residents, and the appearance of distress on the part of the person with dementia (Valleley et al, 2006).

EOP in ExtraCare housing

Our previous research moved the Enriched Opportunities Programme from a theoretical ideal to a practical working model. The assessment process, the provision of individualized activity, the person specification and job description of the EOP Locksmith, staff training needs and the role and responsibilities of the EOP Locksmith, the staff team and the management staff were all clarified through this evaluation. The refined EOP intervention is evaluated here using a robust research design known as a Random Cluster Controlled Trial (RCT). The opportunity arose to undertake this work across extra care housing schemes. Given the increasing emphasis on extra care housing as an alternative to care at home or care-home provision, it was timely to evaluate this new way of working to assess its outcomes systematically here.

The Enriched Opportunities Programme is a multi-level intervention designed to improve the quality of life of those with dementia or other significant mental health challenges. EOP consists of five major elements working together:-

Specialist Expertise

A senior staff member, the “EOP Locksmith”, is employed as part of the senior team who can work with vulnerable individuals and with the team in order to ensure that residents reach their potential for well-being. The title EOP Locksmith was chosen to indicate the key role of unlocking potential for well-being. From previous research we have a clear person specification, job description and training programme for this post.

Individualised Assessment and case work

The EOP Locksmith works with individuals to ensure care is personalised. Specifically they work to enable vulnerable residents to achieve their goals and to identify types of interventions, occupation and activity that are most likely to unlock the potential for well-being and to help them achieve their goals. Case work also ensures that any potential problems are dealt with in a timely manner and liaison with primary and secondary health and care teams is optimised.

Activity and Occupation

The EOP Locksmith takes a lead on ensuring that a programme of activity is in place. This programme is characterised by being variable, flexible and practical to provide opportunity for vulnerable individuals to experience optimum well-being. It is integrated both with the community of the scheme or village and with the wider local community. EOP Locksmiths work with activity coordinators to ensure that the EOP residents can access the mainstream programmes and that any planning includes their needs too.

Staff Training

All staff in the schemes who have any face to face contact with residents received a 1-day training course in person centred care and mental health awareness. In addition, senior staff received a further 3-day course in enabling residents with mental health problems specifically using the Enriched Care Planning approach (May, Edwards & Brooker, 2009). Skills that staff learn on the training course are mentored by the EOP Locksmith in practice.

Management and Leadership

The site manager works closely with the EOP locksmith to ensure that the facilities focus on providing the Enriched Opportunities Programme and to embed this into the pattern of working this over time. In addition, all EOP Locksmiths received support and guidance from the

Senior EOP Operational Coach who has overall responsibility for the EOP across the ExtraCare Charitable Trust.

The Cost of the Intervention¹

The actual costs of any intervention will depend on many organisational variables. Up-front costs for this programme included the following:

- The salary and associated on-costs for the EOP Locksmith
- EOP operational coach management and supervision
- Associated management costs
- Equipment and resources budget
- EOP Locksmith training
- Staff team training

As a guideline cost, operating the EOP over fourteen schemes cost approximately £2,600 per month per housing scheme.

The Research Design

ExtraCare Charitable Trust identified an initial ten extra care villages and schemes that could be involved in the study. Schemes varied in terms of size, larger schemes having over 150 residents, medium schemes having 70-150 residents and smaller schemes having less than 70 residents. The largest scheme – an ExtraCare village had 300 residents and the smallest scheme around 40.

In the current study 5 ExtraCare housing schemes were randomly assigned to receive the EOP for an 18 month period. A further 5 housing schemes were randomly assigned to receive a placebo intervention. It was anticipated that size of scheme might have an effect on the intervention in terms of numbers of individuals identified. For this reason the schemes were randomised but stratified in terms of size of scheme and estimated numbers of residents with problems related to mental health.

¹ These costs are provided as approximate guideline estimates only. They reflect costs over a particular time period and organisational structure.

In the placebo intervention schemes, an extra member of staff called a Project Support Worker Coach (PSWC) was employed for a period of 18 months. The PSWC was an extra member of staff whose remit was to try to increase the activities generally within the scheme. The additional guidance and structures on case work, training or management support was not available within the PSWC schemes. From staff interviews in our previous research, lack of time to provide individualised care was seen as the major barrier for not helping people with dementia achieve an optimal lifestyle. By providing that extra time in the guise of an additional senior member of staff, was a reasonable placebo intervention.

The design of the current study ascertained whether the Enriched Opportunities Programme as a whole intervention has an impact on outcomes or whether the same outcomes can be achieved by just employing an extra staff member. In “research speak” we compared the EOP complex intervention to an attention placebo intervention of the PSWC.

Both the EOP and the PSWC interventions were provided by the ExtraCare Charitable Trust. The research was undertaken by Professor Brooker and her team.

We selected between 20-30 individuals from each scheme who were assessed by the staff team as being at risk of having significant mental health problems. These problems put people at risk of being either marginalised from main-stream participation within the scheme, or of being excluded altogether by having to move out of the scheme.

The sort of resident behaviours that were identified as risk factors included

- confused behaviour such as orientation problems and repetitive questioning;
- communication difficulties such as aphasias or problems caused by significant hearing loss;
- social isolation where residents were reluctant to leave their apartments;
- challenging behaviour such as accusatory behaviour or disinhibited actions;
- and low mood such as sadness, grief and hopelessness.

All residents who met the criteria were approached to see if they would take part. However, any residents were free to take part in the evaluation of the intervention or just the intervention if they wished to

do so. No-one was barred from taking part. The research consisted of tracking the experiences of these individuals over an 18 month period and seeing whether the experience in the EOP schemes made more of a difference to people's lives than the experience in the PSWC schemes.

Given the nature of the intervention it was not possible from a practical point of view for the researchers to be blind to the type of intervention. We seriously considered how to do this but concluded that as soon as the researcher entered a scheme it would be obvious to them whether it was an EOP or a PSWC scheme.

The Research Measures

In order to find out whether EOP and PSWC had a differential impact over time, a repeated measures design was used with each facility having measures taken at four points in time:

- Baseline measures were taken of quality of life and care practice before any intervention occurred. Subsequent change was monitored against this baseline.
- Six months after baseline: the study sites were six months into the implementation of either EOP or PSWC.
- One year after baseline: the study sites were twelve months into the implementation of either EOP or PSWC. At this point the PSWC schemes crossed over to EOP intervention.
- Eighteen months after baseline: Half the study sites had 18 months EOP intervention. The other half had 12 months PSWC and six months EOP.

Given that we already had some data to suggest the efficacy of the Enriched Opportunities Programme in improving quality of life it was decided for ethical reasons that there should be a cross over to full Enriched Opportunities Programme intervention within the placebo control schemes at the 12 month point. This also provided the opportunity to control for the effects of within-scheme variables.

The research consisted of many different lines of enquiry.

Firstly, the identified residents were interviewed on four occasions over the 18 months. They completed various inventories and scales during the interview to assess their quality of life, feelings of depression, their social support and general health and well-being. If they lived with a family member they were also interviewed.

Secondly, a member of staff who knew the resident well rated their levels of dependency and abilities. They also gave their opinion of the person's quality of life.

Thirdly, the researchers looked through the records to monitor any changes and to collect general background information.

Fourthly, the researchers spent time in the public areas of the schemes observing how people were treated and how they engaged in the life of the scheme.

We were also interested in whether the EOP had an impact on how much people used health and social care services so we collected data on this. Also we were interested to see if it impacted on staff attitudes – so staff filled out questionnaires detailing this.

A full list of the standardised measures is provided in Appendix A. These were the measures that we expected to show change based on our intervention. They were chosen carefully so that they optimise response and are valid, reliable and sensitive to change while also being relatively quick and easy to complete. The original questionnaires were brought together in a booklet format to make them easier to complete and understand.

In order to complement the standardised measures, qualitative enquiries were also utilised including ongoing participant case studies as well as focus groups and interviews with scheme staff and residents at the end of the intervention. These interviews and focus groups adopted a semi-structured format in order to facilitate a participatory approach by allowing the participants to identify relevant themes to be pursued.

Gaining Consent to Participate

We consulted with a number of leading researchers in the field of social research in dementia on the issues of how best to provide potential participants with the opportunity to give consent to participate or to decline. Reference was also made to the Royal College of Physicians Report *Guidelines on the Practice of Ethics Committees in Medical Research Involving Human Subjects* (1996), Medical Research Council *MRC Guidelines for Good Practice in Clinical Trials* (1998) and Department of Health (2001).

The consent procedure was seen as a process rather than a one-off event, with individuals being given information about the study on a repeated basis, and a sequence of opportunities being provided to withdraw if this was their wish. Information booklets about the research that were easy

to read were developed with the participant group. The consent procedure followed 3 stages:

Stage 1 A conversation between a staff member and the potential participant occurred during which the staff member showed the resident the information leaflets and asked whether it would be OK for the researcher to visit in order to talk with them about the research. If they agreed, they were given the choice of the researcher visiting them in their apartment or in one of the private sitting rooms in the scheme. They also had the option of having the member of staff or a relative present during the meeting with the researcher.

If agreed, the researcher visited again showing them the Information Leaflets and asked for their permission to spend some time talking about the study. If this was granted, after a discussion based on looking at the leaflet, the resident was asked if they would like to take part. If the person was willing and seemed to be able to understand the request being made of them, the researcher would ask the person to sign a consent form.

Stage 2 If the staff member or researcher considered that the person was not able to understand sufficiently to give meaningful consent, but was not expressing unwillingness or anxiety about the idea of participating, then we provided the next of kin with information about the project, and asked them to sign a document confirming that they know of no reasons why the resident would object or would be adversely affected by participating in the study.

Stage 3 If objections were raised, which could not be resolved through discussion with staff and/or the researcher, then the process would be discontinued.

If no objections were raised the two members of staff who knew the person, signed a document stating that the person seemed unable to understand sufficiently to give meaningful consent, but given that a relative had signed a document confirming that it is unlikely that the person would object, it was intended to proceed with the proviso that further efforts would be made to explain the nature and purpose of the study. If at any time it was felt that the person expressed unwillingness to be involved, their participation was discontinued.

There was absolutely no obligation to take part in the research. If residents decided not to take part it did not affect the care and help that they received. Even if they signed the consent form, they were free to stop taking part at any time without giving a reason.

Following the ethical procedures for obtaining consent, participating residents were asked to complete questionnaires as part of a structured interview with the researcher. This usually took place in the resident's own apartment or within an office in the housing scheme. The interview was split over a couple of meetings if necessary and the participant

could stop at any time they wished or if the researcher felt they were becoming fatigued.

A number of social situations were also observed and evaluated by the researcher using Dementia Care Mapping (DCM). DCM is a tool that comes with considerable guidance over its use in an ethical and inclusive way. All researchers using DCM were trained to advanced level in the use of the tool.

Explanations and consent were sought for all parts of the data gathering including observation at the commencement of the programme. Consent was also ongoing at each observation time. Observation was only undertaken in communal situations in public areas. It took place with the knowledge and consent of those being observed. DCM is a continuous observation and it is quickly apparent to the observer if the participant is uncomfortable about being observed even if they have earlier given their permission. If this occurred the researcher talked with the participant to try to address their concerns. If the participant remained distressed by the observation then the DCM observation was discontinued.

Research Governance

The purpose of this research is to investigate an existing way of working by an RCT. The EOP intervention included individualised case work, an activity programme, staff training and skills development. All the evaluations were by means of questionnaires, interviews and by qualitative research methods. It was a low risk intervention and research programme.

Any distress experienced during the interviews was transient and resolved by the researchers who were skilled at conducting such interviews. Confidentiality and anonymity has been maintained in research outputs and participants had the opportunity to opt out of their involvement at any time.

With regards to the intervention itself, all of the activities offered are such that they could be seen as part of normal care without having to seek ethical approval. There are potential hazards in all activities. ExtraCare staff all work within the framework of Health and Safety Legislation and the Mental Capacity Act to maximise potential for wellbeing whilst minimising risk. Activities within the Enriched Opportunities Programme included reminiscence, music, drama, creative arts, handicrafts, cooking, outdoor pursuits and sensory

stimulation. These activities were risk assessed in line with normal operating procedures.

From our previous research we knew that there was a high probability that being involved in the Enriched Opportunities Programme would be of benefit to participants and at worst it would do no harm. Neither the intervention nor the research methods required any direct clinical procedures or investigations. Participants were not placed at more than minimal risk of physical or emotional harm as a result of any of the research procedures.

Nonetheless, this was a research project and particularly as it involved participants who may have difficulty providing fully informed consent to participate, we felt that it was important that it received ethical approval from a disinterested body. During 2006, however, it was not clear who we should approach to provide the check that we were planning an ethical programme.

We began with the NHS. This project was submitted to COREC at the West Midlands Research Ethics Committee on 19/10/2006 (Project reference number from above REC: 06/MRE07/76.) The outcome was that the committee was of the opinion that the project did not come under the jurisdiction of the NHS REC as participants were not NHS patients. They were of the opinion that University Ethics Committee approval would be sufficient. Subsequently the research was submitted and approved by the University of Bradford Ethics Committee by end of December 2006.

It was raised that we should enquire whether we needed Local Authority Ethics Approval. At this time the system for Local Authority ethics approval was very much a new thing. We contacted known leads in the seven Local Authorities where the research was taking place. We heard from and gained approval from three but did not hear from the others.

In accordance with MRC guidelines for Good Clinical Practice in Clinical Trials 1998, a Steering Group was established to provide overall supervision for the evaluation and to monitor the data. The Steering Group received research reports and interim data analyses at six monthly intervals. They advised on whether the research should continue through to the subsequent stages based on these reports.

The Steering Group comprised of an independent chair and four independent experts in the field of evaluative research/ practice development for older people in extra care housing – particularly those with mental health problems. These group members were not otherwise directly involved with the research. Other members of the Steering Group were the principal investigator, statistician, research assistants,

key operational managers within ExtraCare Charitable Trust and representatives of residents in ExtraCare housing schemes. Membership is listed in Appendix B.

Feedback on research findings were provided to residents and staff through formal and informal presentations at participating sites prior to the publication of this report. Following the publication of this report, articles will be submitted to peer-reviewed journals.



Part 2: Comparing the results of the EOP with the PSWC Intervention.

People were generally very pleased to take part in the research and we had very few people either refusing or dropping out part way through because they didn't like it. Overall 268 residents participated. 135 received the EOP intervention and 133 received the PSWC placebo intervention. After 18 months around 25% of the original group had either died or moved on so that we had 199 remaining - 102 in the EOP and 97 in the PSWC schemes.

Advantages for the EOP Intervention

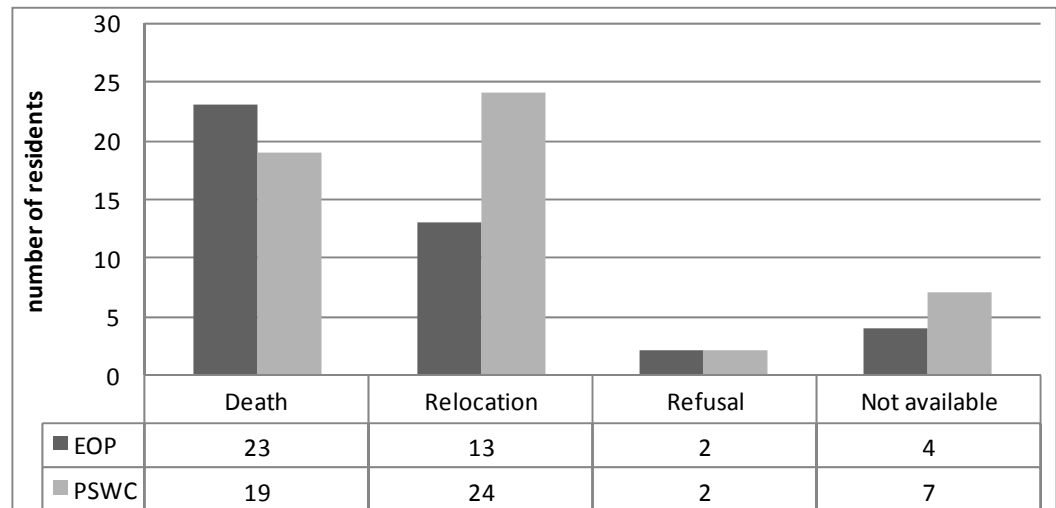
Those in the EOP schemes experienced a number of positive advantages over those residing in the PSWC schemes.

Less likely to have to move out

Over the course of 18 months we lost a number of residents from the study. Sadly forty-two people died although this was not particularly higher in one intervention than the other and was a usual mortality rate for the age of residents taking part. The most striking difference was that residents supported by the EOP intervention were half as likely to

have to relocate to care homes than those supported in the PSWC schemes.

Table 1: Reasons for withdrawal from the programme



22 participating residents moved out of the PSWC schemes to nursing and care homes during the 18 month period whereas only 11 relocated to these types of locations from the EOP schemes. A couple of residents from both types of intervention either moved to another housing scheme or in with family members.

Destination of Relocation	EOP	PSWC
Nursing Home	4	15
Specialist Dementia Home	7	5
Residential Care Home	0	2
Private house with family	2	1
Other extra care housing	0	1

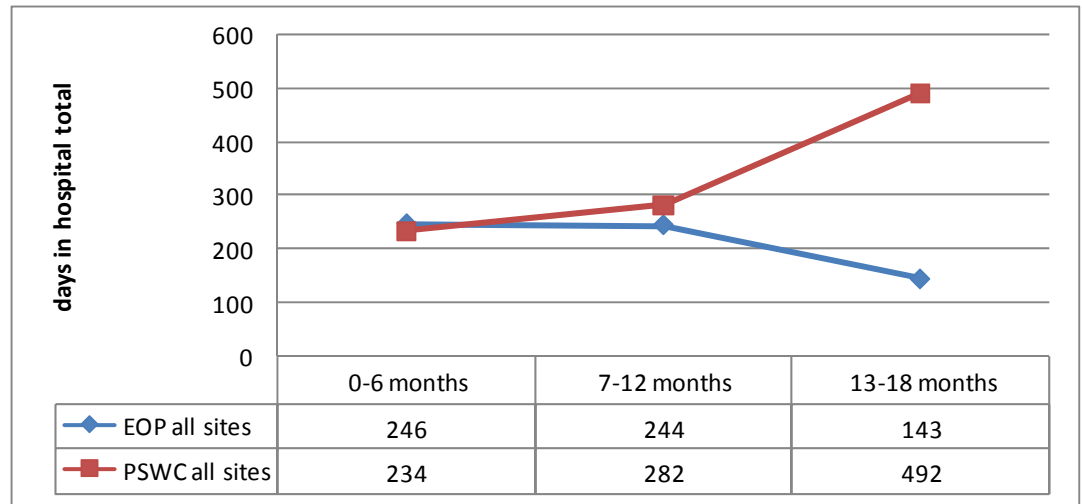
Those who relocated from the PSWC sites were more likely to relocate to nursing home care.

Spent less time in hospital

Overall there was a 42% decrease in hospital in-patient days in the EOP sites over the 18 month period. There was a 52% increase in hospital in-patient days over the same time period in the PSWC schemes. When we look at the patterns of in-patient days at the different sites, there are a

couple of sites in both types of intervention that had low numbers of hospital days throughout the 18 month period. Generally in the EOP sites that had a relatively high number of in-patient days at baseline, the number of days over time decreased. In contrast, the PSWC sites that had a relatively high number of in-patient days to begin with, increased the number still further over time.

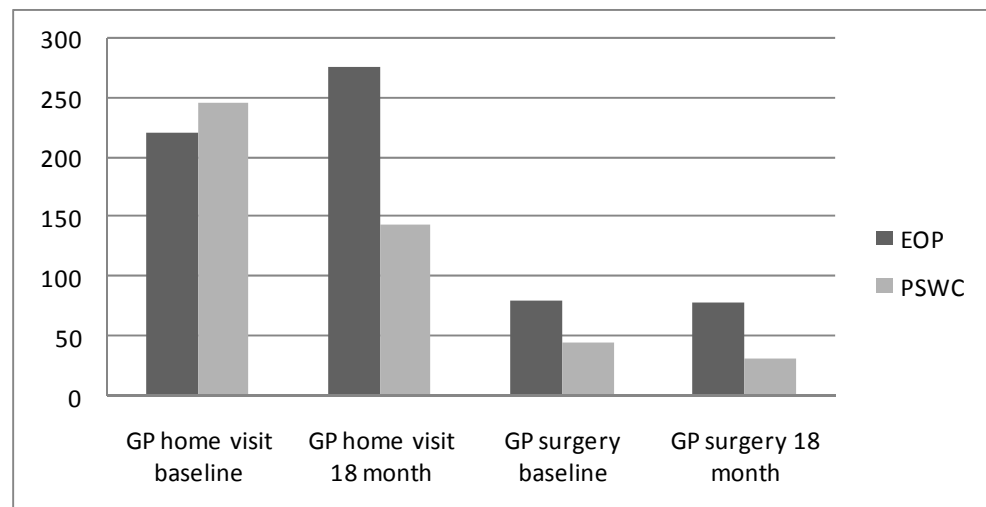
Table 2: Number of days residents spent in hospital



More likely to have a GP visit

The number of GP visits to people at home increased in the EOP group at home and decreased in the PSWC residents overall. The number of visits that residents made to GP's at their surgery remained similar at baseline and 18 months.

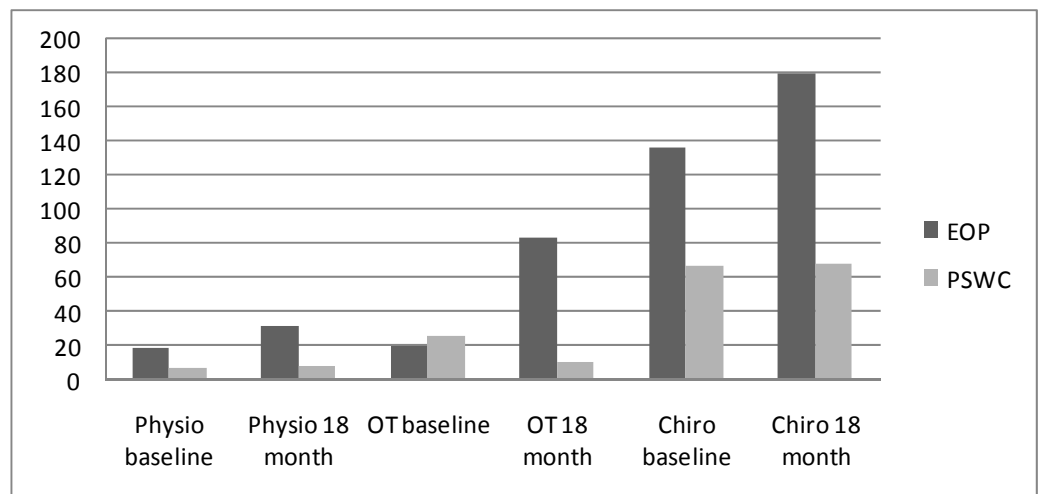
Table 3: Number of GP contacts



More likely to see a community physiotherapist, occupational therapist and a chiroprapist

The number of physiotherapy, OT and chiropody contacts all increased for the EOP sites. These contacts either stayed the same or decreased at the PSWC sites. The contacts with community physiotherapists doubled in EOP sites and remained stable in PSWC schemes. Contact with OT's increased four-fold in EOP but decreased by half in PSWC schemes. Contact with chiroprapists increased by 25% in EOP schemes and remained the same in PSWC schemes.

Table 4: Numbers of contacts with physio, OT and chiropody



Possible explanation for changes in use of health resources

Taken together, it looks as if EOP residents utilised community health resources more as a result of the programme than PSWC residents. This could be because EOP Locksmiths have a specific role in liaising with local health care teams and were either more vigilant in referring people or the residents themselves were more empowered to make appointments. This in turn could have led to less hospital in-patient days.

If this was the case this may also have a bearing on the higher relocation rate to nursing homes in the PSWC group. Deteriorating physical health problems such as infections or medication problems can lead to a hospital admission if they are not treated early. Admission to hospital for a person in this age group can lead to loss of confidence and self care skills. This in turn may then result in residents not feeling in a fit state to return to the housing schemes.

Costs of community health resources and in-patient days

People receiving EOP intervention made greater use of primary and community health care resources compared to those receiving the PSWC intervention. For the EOP intervention this rose from £26,643 in the first 6 months to £35,877 for the final six months. In comparison the PSWC costs fell from £30,269 to £24,702 for the same time period.

On the other hand those in the PSWC schemes had many more in-patient hospital days than those in the EOP schemes. Costs for the EOP residents fell from £58,794 in the first 6 months to £34,177 in the final 6 months. Costs for the PSWC residents rose from £56,646 to £117,589 for the same period of time.

This gives a net difference of a decrease of £15,383 for the EOP intervention and an increase of £55,376 for the PSWC intervention. These both relate to costs over a six-month period. The figures on which the costs are based are drawn from the PSSRU unit costs of health and social care 2008.

Mental health problems more likely to be diagnosed

The incidence of recorded diagnosis of dementia increased in all except one site in the EOP sites. The only EOP site where it didn't increase was the one that had the highest formal diagnosis levels at baseline. The incidence of other diagnoses – usually depression also increased at all the EOP sites. In contrast at the PSWC sites, the incidence of dementia diagnosis increased at 3 sites and the incidence of “other diagnosis” increased at only 2 of the sites.

This may have been due to an increased awareness of the Locksmith and other staff of the importance of diagnosis for treatment.

Less decline in cognitive function

A proportion of participants across all schemes had their cognitive functioning tested directly using a test called the mini-mental state examination (MMSE). Overall 100 people in the EOP schemes and a 104 in the PSWC schemes completed the MMSE at baseline. This test can feel quite threatening for people who are worried about their memory because they will often fail items on it. We had around 25% of study participants who declined to complete the test at baseline and at the end of the research period.

However, we still had a reasonable sample across the study sites. In the table below it can be seen that of the residents completing the test there was a spread of scores from no impairment to some with severe impairment. This shows that the villages schemes were supporting people across the whole range of functioning.

Table 5: Mini mental state Examination scores at baseline and 18 months

	Percentage with score indicating no cognitive impairment (>26)	Percentage with score indicating mild impairment (21-25)	Percentage with score indicating moderate impairment (10-20)	Percentage with score indicating severe impairment (0-9)
EOP				
Baseline	23	23	40	14
18months	32	19	32	18
PSWC				
Baseline	23	33	38	10
18months	31	27	28	4

At 18 months the EOP schemes were continuing to work with a higher proportion of people in the severe category. This may be related to the higher number of relocations from the PSWC sites.

In people with dementia it would be expected that their individual scores would decline over time. Over time, on an individual level for those who had the test repeated, there was no decline in the EOP group. The trend was towards improvement.

In the PSWC schemes, however, there was a significant decline in the performance of individuals on this test over time. The statistical model supporting this is found in Appendix C, Model 1.

Quality of Life rated more positively

Using a standardised questionnaire during an interview, residents were asked to rate their quality of life on a number of different dimensions - physical health; energy levels; mood, living situation, memory, relationship with family & friends; self as a whole; ability to do chores around the house; ability to do things for fun; money/financial situation, and life as a whole.

The ratings of quality of life made by the participants themselves in the EOP schemes rose significantly over the course of the intervention. The ratings of quality of life by participants also rose but not to a significant level until the eighteen month point.

Staff, that knew residents well, also rated residents' quality of life on the same dimensions. Generally staff rated the quality of life of EOP residents better than staff rated quality of life for residents in PSWC

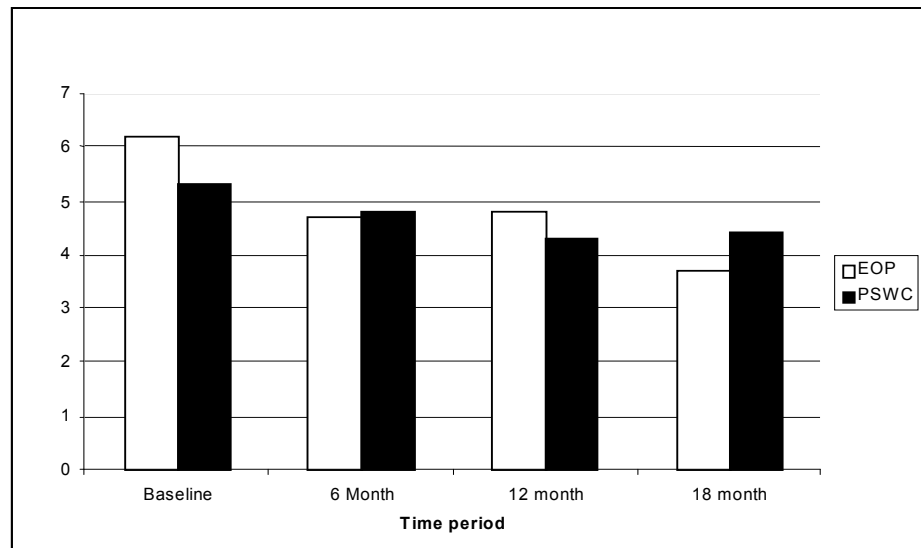
schemes. At 18 months, 6 months after the switch over to EOP, staff in the PSWC schemes rated a significant improvement on the participants' quality of life. The statistical model supporting this is found in Appendix C, Models 2 and 3.

Decreased symptoms of depression

This was assessed during the interview with the residents using a standardised measure of depression. A high score indicates greater feelings of depression. A score of 6 or over indicates that the person may be clinically depressed.

Those in the EOP schemes had a significant and sustained reduction in their self-rating of symptoms and feelings of depression over the period of the intervention. Although there was a downward trend in symptoms in the PSWC schemes this was not sustained to a significant level.

Table 6: Average Geriatric Depression Score



Staff that knew the EOP residents well also rated significantly less signs of depressed mood than staff rated signs in the PSWC schemes.

The statistical model supporting this is found in Appendix C, Model 4.

Feelings of social support maintained

As part of the interview, residents completed a questionnaire about their feelings of being socially supported – particularly in their perceptions of the relationships they experience.

Those residing in PSWC said that they felt less socially supported over time. There was no significant change in how those in the EOP sites felt

over time about the level of social support they received. The statistical model supporting this is found in Appendix C, Model 5.

Gains Made by Residents in both the EOP and PSWC Schemes

There were a number of advantages enjoyed by participants in both interventions. Taken together it would appear that employing an extra member of senior staff increases activity and enjoyment. However, in order to have the added impact on quality of life, levels of depression and feelings of belonging, the extra factors involved in the EOP intervention are necessary.

More activities and more fun

As an indicator of general activity, records were looked at to discover the number of activities that people took part in over the past 4 weeks. There was a great deal of variation both on an individual and site level. Taken as a whole, however, the number of activities that were available to participants increased significantly both at the EOP and the PSWC schemes, although the rate of increase was higher at the EOP schemes. This was particularly the case for activities that were participated in-house rather than outside the schemes.

The enjoyment of activities undertaken in the last 4 weeks was rated on a 1-5 scale. An average enjoyment score was then allocated to each participating resident. Average scores showed a general enjoyment of activities and gradual increases in this enjoyment in both EOP and PSWC sites. The reported enjoyment of activities was consistently higher in the PSWC sites but this difference was not statistically significant. Over time there was an increase in enjoyment of activities at both the EOP sites and the PSWC sites.

The statistical model supporting this is found in Appendix C, Models 6, 7, 8 and 9.

More variety and improved well-being

In-depth observations were undertaken by the researchers at each stage in the communal areas of the schemes. We were particularly interested in observing changes in well-being and diversity of activities that were engaged in. The diversity of activities that people were observed in communal areas within the schemes increased significantly in both the

EOP and PSWC schemes and was actually at its highest in the PSWC schemes 6 months after they had converted to the EOP intervention. Levels of improved and observable well-being in communal areas also improved significantly both in the EOP and PSWC schemes.

The statistical model supporting this is found in Appendix C, Models 10 and 11.

Things that did not change through the intervention

Level of function in activities of daily living

In both the EOP and the PSWC schemes there was a significant decline after 18 months in individuals' ratings of their own dependency and their ability to do every day activities independently. This decline would be expected given the health profile of the people taking part. It may have been that if they had not taken part in the EOP or the PSWC schemes that the decline would have been even steeper. We cannot tell this from the current study. What we can say, however, is that the interventions did not impact differently on dependency over time.

One of the quality of life measures that rated satisfaction with mobility, pain, self-care, activities and anxiety/depression also declined significantly in both the EOP group and the PSWC group.

Satisfaction with level of support remained high

Participants in the EOP and the PSWC sites rated the level of support they received as very good right from the start of the programme. This did not change over the 18 months. They still continued to rate it as very good.

Staff attitudes remained positive

Staff filled in attitude questionnaires at baseline and at 18 months where they answered questions about their attitudes to people with dementia and about caring for older people. These were very positive at baseline and remained so at the end of the measurement period.

Staff turn-over unchanged

There was no noticeable change in staff turn-over through the course of the research.

Part 3: Themes from interviews, focus groups and case studies

In order to complement and supplement the quantitative data in this research, some qualitative methods were also utilised. Focus groups were carried out with non-participating residents and members of onsite staff teams at the end of the intervention. During the same period, one to one interviews were also held with site managers, EOP Locksmiths and the relatives of participating residents. Principles of consent, anonymity and confidentiality were adhered to and proceedings were recorded and transcribed. For the purpose of analysis, transcriptions were then divided into themes and sub themes in accordance with the interpretative phenomenological approach (Smith and Osborn, 2004). A brief summary of these themes are outlined below.

Valuing the EOP Locksmith Role

The EOP Locksmith role was recognised by all the groups interviewed as being crucial to the success of the intervention particularly its importance in resident advocacy;

My views were always very strong before but they're even stronger now. I'm very determined to fight for those residents who've got illnesses. They need looking after and they need someone fighting their corner. A lot of them are on their own they've got no family or next of kin and they need someone there who is looking out for them. (EOP Locksmith)

In addition to their work with residents, EOP Locksmiths were seen as being key to promoting communication and liaison, with staff as well as with relatives and carers:

I do think that mum responds to seeing someone on a regular basis and (the Locksmith) has been that person and it's helping us all to keep on top of what's happening with mum. (Relative)

Staff relationships are brilliant it couldn't get any better I get a lot of respect for what I do. (EOP Locksmith)

However some respondents felt that there was an initial lack of clarity in Locksmith role and the Locksmiths themselves could feel overloaded by the demands placed upon them. These issues diminished over the course of the evaluation as roles became clearer and Locksmiths were advised to focus on a small group of residents at a time:

I had seen Locksmiths as being more activity involved ...my understanding now is that it is working with individuals and understanding why they are as they are really, trying to get to the roots of the problem and then to pass that knowledge on to the key workers and the staff team. (Manager)

I started out thinking I had to solve all their problems from day one and I felt a bit frightened. I think the supervision from the coach has helped tremendously as he suggested I work with five residents at a time...now things have fallen into place and I feel a lot happier. (EOP Locksmith)

Indeed, by the end of the evaluation, Locksmiths tended to express a high degree of job satisfaction:

I've really enjoyed the EOP experience and the learning, the involvement with the residents and getting them out and about. It's been a very uplifting experience. (EOP Locksmith)

I think it's an amazing opportunity to be able to do a job like this. (EOP Locksmith)

The Value of Training

A key feature of the Enriched Opportunities Programme has been the provision of training, not only to Locksmiths but also to the wider staff team. Impressions of the training were overwhelmingly positive:

I understand now how to talk to the residents who do have dementia. Before I used to speak to them like children, now I speak to them like they're proper people. Just because they've got dementia doesn't mean that they can't remember. (Staff Member)

All the other staff say it was the best training they've ever done, it was absolutely fabulous. (Manager)

It makes you more aware doesn't it? I always tend now to get down to their level if they're sitting in a chair and I don't speak behind them or to the side of them. (Staff Member)

However, some felt that they needed more training or regular updates in order to be fully confident in their role:

I think staff actually need more training in dealing with people with dementia because you don't know if you are dealing with things in the right way. (Staff Member)

Integration and Stigmatisation

The Enriched Opportunities Programme was felt to have had a generally positive impact on participating sites, leading to an integration of vulnerable residents:

It has benefited the frailer residents immensely and they've got a much more improved quality of life, they're not sat watching four walls and a television, they're out and about. (EOP Locksmith)

There's a bit more quality time that's spent with the individuals rather than before when it was a little bit of an 'add on' for want of a better word. (Manager)

One of the implications of this greater visibility of vulnerable residents was the perception that schemes were being 'taken over' by such residents, resulting in stigmatising attitudes from some of the wider resident group.

This attitude was particularly apparent in the more newly established villages. As one non participating resident commented:

More than 60 percent of residents think they shouldn't be here, they say it's more like a nursing home.... When extra care was built we all knew from day one that we were going to have these people and that they are entitled to be here as much as anybody else. (Resident)

However, as the intervention progressed it appeared that some of these negative attitudes began to subside, leading to an increasing acceptance of the participating group. As a Locksmith observed of two residents who had previously been ostracised by some:

He's a lot more confident, he's a lot more popular, he's mixing a lot more with people he wouldn't probably have spoken to or they wouldn't have spoken to him. (EOP Locksmith)

She's a lot more integrated with the residents, there are several core residents now that have really taken to her. (EOP Locksmith)

Case Studies

In addition to the qualitative investigations outlined above, six case studies of participating residents were chosen at each site, in consultation with the EOP Locksmith and the resident themselves. Each individual was interviewed at the 6 month, 12 month and 18 month research phases. Corresponding interviews were also carried out with the Locksmith and another care worker who knew the resident well. A summary of six representative case studies from intervention sites are shown below.

Mrs Yellow: Living with dementia in extra care

Mrs Yellow was in her eighties and prior to joining the EOP intervention, had lived in extra care housing for 12 months. Shortly after moving there, she had a stroke and was admitted to hospital. On her return she had become much more confused, was diagnosed as having vascular dementia and was on the verge of being relocated to an EMI care home. She was also isolated, having no visitors and not participating in onsite activities:

I wanted her on the programme purely and simply because of the animosity from the other residents here, they didn't want her here, they said she should never have moved in here and I felt that somebody should be fighting her corner because she had the whole building against her. (EOP Locksmith)

In addition to an advocacy role, the EOP Locksmith liaised with her GP about physical problems such as painful teeth and gained permission to reduce the high levels of Risperidone prescribed to her while she was in hospital.

The EOP Locksmith also introduced a regular volunteer be-friender to visit Mrs Yellow. She subsequently showed a marked improvement after her sedatives were stopped and appeared to become more orientated. She also began joining in activities more and interacting with staff and residents:

She spent a lot of time on her own, her mind wasn't active she was left to her own devices and now she seems to have really picked up. (Staff Member)

Since baseline measures, her abilities in the activities of daily living remained largely stable and there were general improvements in Mrs Yellow's well being including her perceived quality of life, her mental state and her involvement in activities:

The social workers can't believe the change in this lady, she's involved in activities every day, she's in the restaurant every day, goes on shopping trips and day trips out.....She looks a lot better but it's what's inside as well, she's more content, more settled. (EOP Locksmith)

Having avoided her relocation, by the end of the evaluation, the main expressed goal was to enable Mrs Yellow to stay at the site:

I see no reason why we can't at the moment, unless she has another stroke, physically she's quite fit and able. (EOP Locksmith)

Mr Lilac: Enabling a lifestyle change

Mr Lilac was in his late fifties and had lived in extra care housing for eighteen months at the commencement of the EOP intervention. He had experienced many challenges throughout his life. He had become isolated and had lost pride in himself. He had a number of on-going health problems that he had given up attending to.

The EOP Locksmith worked with Mr Lilac through the provision of one to one counselling, liaising with social services about accessing his finances and physical interventions such as getting him a wheelchair, monitoring his diet and prompting in self care activities:

I've worked very closely with (Mr Lilac) in the last 6 months, getting him out and about getting him involved in activities, smartening him up, getting him decent clothes, getting him to wear his decent clothes, tidying

him up a bit better, getting him bathed regularly, getting his medication, taking him to hospital because he's seeing a cardiologist and following that through. In the last 4 visits that he's had he's had his eyes and his ears done, seen the chiropodist and his finances are a lot better now. He's got money every day and he's spending that in the shop". (EOP Locksmith)

Mr Lilac enjoyed individual interaction, particularly going shopping with the EOP Locksmith when he bought some new clothes:

I like going shopping with (the Locksmith). We bought some new clothes and I usually only get them second hand. (Mr Lilac)

He knows that there's someone looking out for him, he loves to see me and he asks for me, we've just got a good relationship and he trusts me. (EOP Locksmith)

By the end of the evaluation, Mr Lilac was taking pride in his appearance, mixed more with other residents and enjoyed music, cards, darts, snooker and bowling as well as having an improved financial situation:

He loves music and the highlight for me was when we got him on the dance floor and I had a lot of comments about it because they were just amazed that he got up and danced, he walks with a frame, not very confident but he got up and danced....He's just a bit more involved than he was before, his neighbours speak to him now, they didn't even know they lived next to him. Because he's got learning disabilities and the way he looks and presents, there were people who said he shouldn't be here that this wasn't the place for him. (EOP Locksmith)

Mrs Black: Living with depression in extra care housing

Mrs Black was a lady in her eighties who had no signs of cognitive disability but who had struggled for many years with clinical depression. She was initially happy after moving into the extra care housing two years earlier but gradually became isolated from other residents and mistrusting of staff, particularly relating to her medication. At the start of the intervention, staff reported that she had become very depressed. They had serious worries that she might do herself harm and had taken control of her medication.

She's got a lot of problems and she needs company and to get out of her flat and to make new friends. (Staff Member)

After joining the EOP intervention, the EOP Locksmith encouraged her to become involved in activities and spent one to one time with her:

We've become very good friends, she trusts me 100 percent. (EOP Locksmith)

The fact that she, in consultation with the staff team, had now recovered control over her medication had also been positive for her and helped to restore her trust in the staff who had themselves been encouraged to adopt a coordinated and consistent approach in interactions with Mrs Black. Her greater involvement in activities had also seen positive changes in Mrs Black's mood:

(The Locksmith) encourages me to go and join in if she didn't I probably wouldn't go and I'd get depressed again. Yesterday I thought I don't want to stay in this flat all afternoon so I put my shoes on and went down. (Mrs Black)

By the end of the evaluation, staff reported that Mrs Black had become more trusting, calm, relaxed and sociable:

If she's got a low day she knows that she has the Locksmith and staff around her so that she won't feel isolated. (Staff Member)

In addition, from our structured observations, it could be seen that Mrs Black's involvement in and enjoyment of activities and level of independence in the activities of daily living had markedly improved throughout the intervention. Her perception of her quality of life was also much better and her reports of symptoms of depression had correspondingly decreased.

Mr Blue: Coping with caring and bereavement

Mr Blue was in his seventies and had lived in extra care housing for many years. He had initially moved there as he needed help in looking after his late wife who had dementia:

We came to here because of my wife's health and keeping up the family home was no longer viable. We looked at all sorts of options like stair lifts and came to the conclusion that it would be better if we were on one level. Having made that decision we'd already been volunteers at this scheme and the manager suggested that we should apply to come in. (Mr Blue)

He did not regret his decision to relocate, for not only did he get support in his wife's care but his social horizons were also broadened:

I thought my horizons would be reduced but I think I discovered when we moved in that actually my horizons were increased. Because things that I would not have been able to do because of the responsibility of caring for my wife, I was able to do in this environment as there was always someone to look after her. So with no feeling of guilt I was able to leave her on odd occasions and do something else. (Mr Blue)

He was selected to take part in the programme because, after the death of his wife about a year ago, he had become clinically depressed:

Being on my own has been incredibly difficult and I'm still adjusting to that. Having been a carer for so many years, you get to the situation where the care is no longer required but you're still a carer at heart, so up to a point you're living in a bit of a vacuum. (Mr Blue)

He also had a tendency to hide his true feelings and put up barriers:

Its like a defence mechanism, it's not the real me but it's the one I let people see. (Mr Blue)

Throughout the intervention, the EOP Locksmith gave Mr Blue individual attention and acted as a point of contact for him. She also tried to raise staff awareness of depression and its manifestations. The assistance given was a two way process as Mr Blue, in his former caring role, had gained expertise in the area of dementia:

He has actually helped me loads, he's given me information about Alzheimers and dementia care and he's escorted me to a meeting of the Alzheimers Society. (EOP Locksmith)

We've helped each other to an extent. She's helped me when I've been really low and still going through the process of bereavement and I've helped her to a certain extent. (Mr Blue)

He enjoyed discussing his feelings with the EOP Locksmith as well as with other bereaved residents:

I've found living here that, as someone on their own, I'm nobody special because everyone's on their own. (Mr Blue)

He also began to mix more, joined a relaxation programme and a men's group. He reported enjoying life more and experienced fewer depressed symptoms.

The CPN came to see me yesterday and said that I'd be taken off their list as I had made the sort of progress that they hadn't anticipated. (Mr Blue)

Mrs Orange: Living with sensory disability in extra care

Mrs Orange was in her eighties and had lived in extra care housing for about 9 months. She had moved from her former home due to physical problems relating to her eyesight, hearing and mobility:

That's what stopped me, my sight, I do wish they could do something, its what they call age related macular degeneration. I think it'll go on age, they'll treat the younger people first. Age does depend on a lot of things so I don't think I've got much chance. (Mrs Orange)

She was a widow, her daughter had died and she only had contact with her grandson who she did not want to be a 'burden' to:

At first I couldn't really settle, they told me I could do as I like in my own flat, you can please yourself, you've got your independence, which I didn't expect. But I also thought, I've only got a grandson and all the problems would be on his shoulders which isn't fair so I decided to come. (Mrs Orange)

As a result of her physical impairments, combined with her great independence and corresponding unwillingness to ask staff for help in attending activities, she had become increasingly isolated:

I don't bother the staff unless I've got to... If I wanted to go and mix I could, it's not that I don't want to, its just that I can't see to do flower arranging and things like that I don't go up much for anything...I would have liked to do the gardening, I'm not a card player but I like dominoes...I know they have a pub meeting upstairs but I don't go because I cant hear so I don't really go out much at all. (Mrs Orange)

Throughout the Programme, the EOP Locksmith provided encouragement and assistance to Mrs Orange and liaised with relevant outside agencies:

I've been spending time with her one to one. Its not personal care, its things like opening tins, reading instructions on microwave labels...one of the ladies that has worked with us in the past from the sensory impairment team is booking in training with us on sensory impairment and were all going to learn about how things need to be like serving a persons meal, meet needs to be at 12 o clock, potatoes at 6 o clock. (EOP Locksmith)

The Locksmith also gave Mrs Orange assistance with some tasks such as new hearing and sight aids, in order to maximise her independence:

I'd like to be able to see a bit better and to do things. I'd like to be able to hear a little bit better I can hear a bit with all these contraptions and I'd like to be able to do things all for myself. (Mrs Orange)

While Mrs Orange experienced further deterioration in her hearing and eyesight throughout the intervention, she also experienced an improvement in her perceived quality of life, benefiting from the aids

and adaptations obtained for her, developing a good relationship with the Locksmith and becoming more involved in social activities:

*She never went on trips before but in the last few months she has.
(EOP Locksmith)*

Mrs White: Facilitating integration and involvement

Mrs White was a lady in her seventies and had lived in extra care housing for two years. She had formerly lived alone in warden-controlled accommodation. At the beginning of the EOP intervention staff were aware that she had been diagnosed with dementia. She had also become isolated and did not like the fact that, for health and safety reasons, her access to cigarettes was controlled by staff. This issue had been the source of much conflict between Mrs White and the staff team:

The carers bring me 20 every morning but I think they should be in my flat and not in their room, they control my cigarettes and that I do not like. I feel controlled. (Mrs White).

The EOP Locksmith liaised with the local GP and her daughters and devoted much one to one time with Mrs White. She aimed to get her more involved in organised activities and to help her understand why her access to cigarettes was controlled:

She's been encouraged to join in things and to not spend as much time on her own which I don't think is a good thing. (EOP Locksmith)

The Locksmith also encouraged staff to adopt a more flexible approach in interactions with Mrs White, incorporating lots of gentle encouragement and respect.

It's a fine line with (Mrs White) and you've got to respect her decision if she doesn't want to join in. (EOP Locksmith)

Her physical well being was monitored, with an infection being identified and treated and assistance being given in self care:

(Mrs White) had a terrible infection but because people were saying that she's got dementia, they put her behaviour down to that but once they sorted the infection out things got a lot better. People tend to pass if off don't they and really that's everybody's fault. (EOP Locksmith)

Mrs White enjoyed the one to one attention from the EOP Locksmith and began to see her as a point of contact in the staff team:

The one to one worked well she's built up a good relationship with (the Locksmith)...she's seen a lot of changes and she needs to build up a

good relationship with a few members of staff rather than a lot. (Staff Member)

By the end of the intervention, Mrs White had become more settled, her relocation to a care home had been avoided and her integration and involvement in the life of the site had improved:

I think (Mrs White) was chosen for the programme because of her illness, she was getting worse she was getting more and more isolated and agitated. It was quite sad to see the change but since she started joining in more there's been a change in her. (Staff Member)

Final thoughts

The results of the EOP are very positive. This has been a complex intervention operating as it does on a number of different levels. We have continued to learn about the intervention along the way. The feeling on the front-line is that if we were starting over again now, we could achieve significant change more quickly. The EOP way of working has been rolled out in a further four ExtraCare villages and continues to change the lives of people who face significant problems.

What surprised us most was, that in a relatively short period of time, the different elements of EOP did not just lead to an improved quality of life for people with significant mental health problems but also had a big impact on relocations and hospital bed-days. The efficacy of this intervention is compelling both from a quality of life perspective and from an economic one.

Links to the National Dementia Strategy

This programme of research and practice development has implications and lessons around a number of key objectives within the strategy.

Objective 1: Improving public and professional awareness of dementia

During the development of the programme we have gained a lot of experience in how to work with the stigma that surrounds dementia. The extra care housing schemes where we have worked are general mixed tenancy schemes and villages. People move into them to enjoy an active lifestyle. These are not dementia specialist establishments. Nonetheless, given the age profile of residents a good proportion will develop dementia or depression. The reaction of the residents without dementia has been a strong factor in determining the quality of life of the group of people who have been on the EOP programme. We have developed ways of decreasing stigma and continue to work on this.

Objective 2: Good quality early diagnosis and intervention for all

In all the ExtraCare housing schemes at baseline very few people had a formal diagnosis. This increased substantially over the first part of the programme. The EOP locksmith was able to work directly with people to help them seek out a diagnosis and to receive appropriate intervention.

Objective 4: Enabling easy access to care support and advice following diagnosis

In this programme of work we have many examples of the EOP Locksmith spotting when people were having health or support problems and enabling them to access the help that was needed quickly. There are a number of case studies where people's behaviour was disturbed due to over-medication or untreated infections that the Locksmith was able to work with the primary care team to ameliorate. The increased contact with GP's, community physiotherapists, occupational therapists and chiropodists was an example of this.

Objective 6: Improved community personal support services

The support provided within the EOP extra care housing was available to all. The EOP Locksmith ensured that people living with dementia and their carers were able to access these services in a timely manner. By targeting those known to be most at risk of being excluded from the housing schemes enabled them to receive the optimal personal support services.

Objective 8: Improved quality of care for people with dementia in general hospitals

In the EOP programmes there were many case reports of residents being discharged from hospitals more quickly because of the EOP locksmith support and level of staff training that was available to the person following discharge. This is also evident in the many fewer hospital bed-days observed in the EOP ExtraCare housing schemes.

Objective 10: The potential for housing support, housing related services and telecare to support people with dementia and their carers.

The EOP is the first well described and evidence based intervention for people with dementia living in general extra care housing. The EOP locksmith role, the staff training and the leadership support mean that people who have made a housing lifestyle choice can continue to enjoy this and not have to move onto more restrictive care environments without good cause. The EOP locksmith is in an excellent position to ensure telecare is used appropriately to maximise independence.

Objective 11: Living well with dementia in care homes

The EOP Locksmith is a prime example of a leadership role for dementia in care homes and in extra care housing. The impact that the EOP had in care homes and extra care housing that were already providing a reasonable standard of care for people with dementia is testament to this. What we have learnt through a long period of research and development is that the EOP Locksmith roles are not easy roles to undertake. Individual EOP Locksmiths have all commented on the stress inherent in the role and the need for it to be well supported by strong general management and access to external expertise and supervision. Having the EOP Locksmith in place means that in-reach from CMHT's and external therapists and specialists becomes much more effective.

Objective 12: Improved end of life care for people with dementia

The EOP locksmith is in a good position to ensure that end of life care is optimal and accords with individuals wishes and needs. Being an expert in dementia and knowing the person well, means that when the time comes they can use their skills and knowledge. Again we have a number of case reports that pay testament to the EOP Locksmith role both in working directly with individuals and their families, with the staff team and with primary care and palliative care agencies.

Objective 13: An informed and effective workforce for people with dementia

Throughout the development of EOP the skills of the workforce have been a key focus. We have a good evidence base for the knowledge and skills set necessary to deliver good person centred care. The mentoring skills and on-going support of the EOP Locksmith in maintaining this skill set should not be under-estimated. Training without leadership does not change practice for long.

Next steps

ExtraCare Charitable Trust is committed to retaining the Enriched Opportunities Programme in all its housing schemes and villages. At the beginning of the randomised controlled trial, the ExtraCare Charitable Trust felt that this approach would bring benefits to residents. What the trial has established is that the benefits are considerable both in terms of quality of life, improved mental health and the ability to age well in a place where people have made a conscious choice to live. We are able to support people in their personal choices. We feel confident now that this is the right model for supporting people longer term.

Even prior to the publication of this report, the EOP intervention has been held up as a model example of good practice. The Enriched Opportunities Programme won a prestigious National Charity Award in the category of Healthcare and Medical Research in June 2009.

Up until now EOP has been funded by charitable giving. We will continue to work on this model until longer term funding can be identified and applied.

We continue to evolve the model in practice. For example as EOP Locksmiths become more established we are investigating whether

having one Locksmith working across 2 sites is possible without diluting the impact of the intervention.

We are currently working on a series of practice guidelines around the implementation of the different elements of the EOP. We also want to formalise the role of training and education interventions to support the development of the intervention.

The research will be written up for peer reviewed journals and a number of conference presentations are planned both in academic and practitioner forums over the next twelve months.

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APPENDIX A SUMMARY OF MEASURES

Description of the target population and selection criteria included

- Enriched Opportunities Inclusion Criteria (devised for the study).
- BADLS Bristol Activities of Daily Living Scale (Bucks et al, 1996):
- BARTHEL Inventory (Mahoney & Barthel 1965);
- The mood scale of the BASOLL Behavioural Assessment Scale of Later Life (Brooker, 1997);
- Mini Mental State Examination MMSE (Folstein et al, 1975)

The selected standardised outcome measures included

- Quality of Life – the QOLAD (Logsdon et al, 2000) and the EQ5D (Brooks, 1996)
- Impact on observed well-being during social activities: Dementia Care Mapping (Bradford Dementia Group, 2005: Brooker, 2005)
- Perceived levels of social support e.g. Duke Social Support Index (DSS; Koenig et al, 1993).
- Impact on psychiatric morbidity; Geriatric Depression Scale; GDS (Sheikh & Yesavage, 1986) SF 12 (Ware et al 2002).
- Impact on staff attitudes and behaviour ADQ Approaches to Dementia Questionnaire (Lintern & Woods, 1996);

In addition the following data was collected at each stage in each facility

- Level of activity; Number of activities that the participant has taken part in the past 4 weeks both within the scheme and outside of it. Participants will be asked to rate their enjoyment of the various activities on interview.
- Number and type of relocation to alternative care environment (e.g. nursing home)
- Mortality rate i.e. number of deaths, and duration of residence prior to death, follow-up mortality rates on residents who have moved into nursing homes.
- Number of significant health events (e.g. falls), number of hospital in-patient days
- Staff turn-over

For those residents who were unable to cope with pen and paper tests we also carried out key worker (staff) proxy reports of quality of life and well-being. All researchers will be experienced interviewers of older people and will endeavour to collect direct reports where ever possible.

Given the novelty of the intervention and the lack of sensitive standardised measures that have been used with this population, we undertook some qualitative enquiries to ensure we captured the full

impact. These included case studies with participants and focus groups with staff, Locksmiths, Project Support Worker Coaches, scheme managers and non participating residents which took place at the end of the intervention. Case studies were also undertaken on 3 participants per site including those with live-in family members.



APPENDIX B STEERING GROUP MEMBERSHIP

Position	Name	Title & Organisation
Chair	Jeremy Porteus	Housing Network lead in CSIP Care Services Improvement Partnership at the Department of Health
Independent Expert	Martin Orrell	Professor of Old Age Psychiatry University College London
Independent Expert	John Keady	Professor of Mental Health Nursing University of Manchester
Independent Expert	Jan Oyebode	Director of Clinical Psychology Training, University of Birmingham
Independent Expert	Ann Netten	Health Economist; Professor at Personal Social Services Research Unit, University of Kent at Canterbury
Extra Care Housing Residents' perspective	Jim O'Hagen	Resident at Beacon Park
Extra Care Housing Residents' perspective	Peter Andrew	Resident at Reeve Court Village
ExtraCare Charitable Trust Lead	David Campey (Steve Burnell to deputise on occasion)	Director of Fund Raising ExtraCare Charitable Trust
ExtraCare Charitable Trust Operational management of Enriched Opportunities Programme	Lorraine Haining & Guy Page	Operations Coach ExtraCare Charitable Trust
Principal Investigator	Dawn Brooker	Professor of Dementia Studies, University of Worcester (formerly Bradford)
Research Team Statistician	Andy Scally	Senior Lecturer University of Bradford
Research Assistant	Elaine Argyle	Bradford Dementia Group University of Bradford
Research Assistant	David Clancy	Bradford Dementia Group University of Bradford

APPENDIX C STATISTICAL ANALYSIS & MODELS

All outcome measures were analysed using a linear mixed model in Stata Release 9.2. This type of model takes appropriate account of the two levels of clustering of the data: outcome measures on the same individuals on repeated occasions, and clustering of individuals within care homes. The main effects of group and time were incorporated as factors in the models and a group-time interaction was also included. Time was, on occasion, incorporated as a covariate rather than a factor when there appeared to be a linear trend with time. The group-time interaction terms identify any differential effect, over time, on the outcome measures between control and intervention groups. An Identity covariance structure was used for each model. For all compound scales, where responses for individual elements were missing, the mean score over the completed elements was imputed.

Model 1

Cognitive function Mini-Mental State Examination MMSE model summary

```
Wald chi2(3) = 7.01
Log likelihood = -1196.1027 Prob > chi2 = 0.0716
```

mmse	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
__Igroup_1	-2.090652	1.110422	-1.88	0.060	-4.26704 .085735
__Itime_1	-1.250031	.536061	-2.33	0.020	-2.300691 -.1993707
__IgroXtim_~1	1.601262	.7367037	2.17	0.030	.1573492 3.045175
__cons	20.62242	.793841	25.98	0.000	19.06652 22.17832

At baseline the mean MMSE score was slightly higher in the control group (20.6) than in the intervention group (18.5, $p=0.06$). At 18 months, in the control group the MMSE had fallen by 6% ($p=0.02$) and in the intervention group it had risen slightly by 1.7% ($p=0.03$ for the group-time interaction).

Model 2 Quality of Life QALAD (QAD1) self rated model summary

There was a significant group-time interaction for QAD1 ($p<0.001$). The baseline mean score for the control group (29.0) did not differ significantly from the baseline mean score of the intervention group (27.6, $p=0.41$ for the difference). For the control group, the mean score was slightly higher at all three subsequent time points, but only the 18 month mean score was

significantly higher (1.3 units (4.5%), $p=0.033$). In the intervention group there was a step increase in the baseline score at 6 months that was maintained fairly consistently at 12 and 18 months. Over the three periods the increase averaged 3.1 units (11%, $p<0.001$).

Quality of Life QALAD (QAD1) self rated model summary

Wald chi2(7) = 87.63
 Log likelihood = -2836.4251 Prob > chi2 = 0.0000

qad1tot	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
_Igroup_1	-1.416792	1.70278	-0.83	0.405	-4.754181 1.920596
_Itime_1	.9570956	.5218835	1.83	0.067	-.0657773 1.979968
_Itime_2	.279143	.5567138	0.50	0.616	-.8119959 1.370282
_Itime_3	1.278914	.5997445	2.13	0.033	.1034366 2.454392
IgroXtim~1	2.711594	.741061	3.66	0.000	1.259141 4.164047
IgroXtim~2	3.470543	.7860127	4.42	0.000	1.929987 5.0111
IgroXtim~3	3.157808	.8241032	3.83	0.000	1.542596 4.773021
_cons	28.98651	1.205176	24.05	0.000	26.62441 31.34861

Model 3

QOLAD Staff-rated (QAD2) model summary

Wald chi2(7) = 36.94
 Log likelihood = -2717.274 Prob > chi2 = 0.0000

qad2tot	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
_Igroup_1	-2.014146	.8180156	-2.46	0.014	-3.617427 -.410865
_Itime_1	.5237707	.4802825	1.09	0.275	-.4175657 1.465107
_Itime_2	.2707675	.5095124	0.53	0.595	-.7278584 1.269393
_Itime_3	-.9786109	.5344967	-1.83	0.067	-2.026205 .0689833
IgroXtim~1	1.955731	.6803332	2.87	0.004	.6223026 3.28916
IgroXtim~2	.8985624	.7148214	1.26	0.209	-.5024618 2.299587
IgroXtim~3	2.391054	.7498336	3.19	0.001	.9214068 3.8607
_cons	31.28993	.5781573	54.12	0.000	30.15677 32.4231

For QAD2, there was again a significant group-time interaction ($p=0.0043$). The mean score at baseline was 31.3 in the control group with a slightly, but significantly ($p=0.014$), lower value of 29.3 in the intervention group. In the control group, from an initial, non-significant ($p=0.28$), slight increase of 0.5 units at 6 months from the baseline score, there was subsequently a small but statistically significant ($p=0.01$) downward trend. At 18 months the mean score was 1.0 unit (3%) lower in the control group than at baseline. This was not significant ($p=0.067$). In the intervention group the mean QAD2 had increased by 2.0 units (6%, $p=0.004$) at 6 months, fell back slightly to 3% above baseline ($p=0.21$ for the difference from baseline) at 12 months and improved again to 8% ($p=0.001$) above baseline at 18 months.

Model 4

Depression Rating Scales GDS model summary

Log likelihood = -2341.7563 Wald chi2(7) = 52.62
 Prob > chi2 = 0.0000

gdstot	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
._Igroup_1	1.016443	.5428131	1.87	0.061	-.0474509	2.080337
._Itime_1	-.3122082	.334429	-0.93	0.351	-.9676769	.3432606
._Itime_2	-.7984585	.3547735	-2.25	0.024	-1.493802	-.1031152
._Itime_3	-.487376	.3707359	-1.31	0.189	-1.214005	.2392529
._IgroXtim_~1	-1.307386	.4731455	-2.76	0.006	-2.234734	-.3800379
._IgroXtim_~2	-.8360688	.4976351	-1.68	0.093	-1.811416	.139278
._IgroXtim_~3	-1.862049	.5211234	-3.57	0.000	-2.883432	-.840666
._cons	5.260674	.3836121	13.71	0.000	4.508808	6.01254

For GDS the group-time interaction term was significant ($p=0.0025$). The model estimate for the mean GDS score at baseline was 5.26 for the control group and 6.28 for the intervention group; this difference was borderline significant ($p=0.06$). For the control group the GDS score at subsequent time points was consistently lower, though the only statistically significant change was a fall of 15% at 12 months ($p=0.024$). The reductions from baseline of 6% ($p=0.35$) and 9% ($p=0.19$) at 6 and 18 months respectively were not statistically significant. For the intervention group there was reduction in GDS score from baseline of 26% at both 6 and 12 months and a 37% reduction at 18 months (all $p<0.001$). [NOTE: see comments for BASOLL; the same will be true for all further % changes where significant interactions are present]

Model 5

Perception of social support DSSIS model summary

Wald chi2(3) = 16.16
Log likelihood = -2354.08 Prob > chi2 = 0.0010

dssist	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
_____+						
_Igroup_1	-1.627132	.5074806	-3.21	0.001	-2.621775	-.6324879
time	-.3801349	.123649	-3.07	0.002	-.6224826	-.1377872
_IgroXtime_1	.3574819	.1743195	2.05	0.040	.0158219	.6991419
_cons	18.58055	.3582718	51.86	0.000	17.87835	19.28275
_____+						

At baseline the mean DSSIS score in the control group was 18.6. In the intervention group the mean baseline score was slightly lower, at 17.0, and this difference, though small, was statistically significant ($p=0.001$). In the control group there was a significant linear trend for the DSSIS score to fall by 0.4 units (2%) per 6 month period ($p=0.002$). In the intervention group the DSSIS score was fairly stable, with a very slight and non-significant ($p=0.85$) [NOTE: not shown in table] downward trend of 0.02 units (0.1%) per 6 month period. The group-time interaction was borderline statistically significant ($p=0.04$).

Model 6 Number of activities (within the scheme) model summary

For 'No. activities within' there was a significant group-time interaction ($p=0.02$). At baseline the average 'number of activities within' undertaken was 11.3 in the control group and 14.2 in the intervention group, though the difference was not statistically significant ($p=0.35$). In the control group the mean number of activities increased progressively over the three subsequent six month periods, with an increase of 27% above baseline at 6 months ($p=0.22$), 70% at 12 months ($p=0.004$) and 117% at 18 months ($p<0.001$). In the intervention group there was a 87% increase at 6 months ($p<0.001$), which was maintained at 84% above baseline at 12 months ($p<0.001$) and rose further to a 151% increase at 18 months ($p<0.001$).

Number of activities (within the scheme) model summary

Wald chi2(7) = 122.57
 Log likelihood = -3315.0141 Prob > chi2 = 0.0000

mact10w	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
_Igroup_1	3.851136	4.129966	0.93	0.351	-4.243448	11.94572
_Itime_1	2.960415	2.43293	1.22	0.224	-1.808041	7.72887
_Itime_2	7.858239	2.692771	2.92	0.004	2.580504	13.13597
_Itime_3	13.1689	2.745488	4.80	0.000	7.787844	18.54996
IgroXtim~1	9.307843	3.247573	2.87	0.004	2.942717	15.67297
IgroXtim~2	4.019518	3.521924	1.14	0.254	-2.883325	10.92236
IgroXtim~3	8.229984	3.57893	2.30	0.021	1.215411	15.24456
_cons	11.25683	3.001147	3.75	0.000	5.374692	17.13897

Model 7

Number of activities outside the scheme model summary

Wald chi2(4) = 14.35
 Log likelihood = -1806.3738 Prob > chi2 = 0.0063

mact10o	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
_Igroup_1	.0573398	1.540607	0.04	0.970	-2.962194	3.076873
_Itime_1	1.935562	.5435084	3.56	0.000	.8703049	3.000819
_Itime_2	1.663779	.5708201	2.91	0.004	.5449922	2.782566
_Itime_3	1.376544	.5789507	2.38	0.017	.2418216	2.511266
_cons	2.957576	1.196627	2.47	0.013	.6122294	5.302923

For activities outside the group-time interaction was not statistically significant (p=0.16). At baseline the mean number of outside activities was not significantly different between the two groups (an average of 3.0 activities for each group, p=0.97 for the group difference). At 6 months this increased by 65% above baseline (p<0.001) in both groups, fell slightly to 55% above baseline at 12 months (p=0.004) and to 46% at 18 months (p=0.017). All increases were statistically significant but the slight decline was not (p=0.60).

Model 8

Number of activities (total) model summary

Wald chi2(7) = 129.77
Log likelihood = -3451.3717 Prob > chi2 = 0.0000

mact10t	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
__Igroup_1	4.881745	4.530931	1.08	0.281	-3.998716	13.76221
__Itime_1	3.211521	2.505515	1.28	0.200	-1.699198	8.12224
__Itime_2	8.691735	2.759257	3.15	0.002	3.28369	14.09978
__Itime_3	11.66331	2.782294	4.19	0.000	6.210115	17.1165
__IgroXtim_~1	11.34833	3.380515	3.36	0.001	4.722637	17.97401
__IgroXtim_~2	3.739765	3.644432	1.03	0.305	-3.403191	10.88272
__IgroXtim_~3	12.03277	3.688508	3.26	0.001	4.803426	19.26211
__cons	11.96019	3.271956	3.66	0.000	5.54727	18.3731

For 'total number of activities' there was a significant group-time interaction ($p < 0.001$). At baseline the model estimate of the average 'total number of activities' undertaken was 12.0 in the control group and 16.9 in the intervention group, though the difference was not statistically significant ($p = 0.28$). In the control group the mean total number of activities increased progressively over the three subsequent six month periods, with an increase of 27% above baseline at 6 months ($p = 0.20$), 73% at 12 months ($p = 0.002$) and 98% at 18 months ($p < 0.001$). In the intervention group there was a 86% increase at 6 months ($p < 0.001$), which was broadly maintained at 73% above baseline at 12 months ($p < 0.001$) and rose further to a 140% increase at 18 months ($p < 0.001$).

Model 9 Enjoyment of activities model summary

For enjoyment of activities the group-time interaction was not statistically significant ($p = 0.66$). At baseline the mean enjoyment of activities score was not significantly different between the two groups (an average of 3.8 for the control group and 3.6 for the intervention group, $p = 0.61$ for the group difference). At 6 months this increased by 10% above baseline ($p < 0.001$) in both groups and was maintained at 12.4% above baseline at 12 months ($p < 0.001$) and at 11.6% above baseline at 18 months ($p < 0.001$). The differences between the average enjoyment scores at the three time points post baseline were not statistically significant ($p = 0.65$) [NOTE: not shown in table].

Enjoyment of activities model summary

Wald chi2(4) = 33.44
Log likelihood = -1329.2342 Prob > chi2 = 0.0000

actenjm	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
__Igroup_1	-.1946118	.3766846	-0.52	0.605	-.9329	.5436765
__Itime_1	.3740059	.0873888	4.28	0.000	.202727	.5452849
__Itime_2	.4577031	.0917297	4.99	0.000	.2779161	.63749
__Itime_3	.4264022	.0961214	4.44	0.000	.2380077	.6147966
__cons	3.821733	.2711147	14.10	0.000	3.290358	4.353108

Model 10

Occupational diversity from DCM data model summary

Wald chi2(7) = 51.61
Log likelihood = -833.14224 Prob > chi2 = 0.0000

occddiv	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
__Igroup_1	.1852191	.2826686	0.66	0.512	-.3688011	.7392393
__Itime_1	.6957924	.2107677	3.30	0.001	.2826953	1.108889
__Itime_2	.4304461	.214004	2.01	0.044	.011006	.8498862
__Itime_3	1.336751	.2265815	5.90	0.000	.8926596	1.780843
__IgroXtim_~1	.080876	.2936757	0.28	0.783	-.4947177	.6564697
__IgroXtim_~2	.0709146	.3021649	0.23	0.814	-.5213177	.6631469
__IgroXtim_~3	-.8411338	.3104334	-2.71	0.007	-1.449572	-.2326955
__cons	1.824047	.2002243	9.11	0.000	1.431615	2.21648

For occupational diversity there was a significant group-time interaction ($p=0.006$). At baseline the mean 'occupational diversity' was 1.8 in the control group and 1.6 in the intervention group, though the difference was not statistically significant ($p=0.51$). In the control group the mean occupational diversity increased by 39% above baseline at 6 months ($p=0.001$), fell slightly to 24% above baseline at 12 months ($p=0.04$) and rose again to 74% above baseline at 18 months ($p<0.001$). In the intervention group the increase was 49% at 6 months and 31% above baseline at 12 months, but these increases were not statistically significantly different from those in the control group

($p=0.78$ and $p=0.81$, respectively). At 18 months in the interventional group the occupational diversity was 31% higher than at baseline, which though significantly higher than baseline ($p=0.02$) represented a significantly lower increase than that obtained in the control group at 18 months ($p=0.007$).

Model 11

Observed Well-being in residents with over 24 observations

Wibs model summary (tf>24)

Wald chi2(4) = 65.76
 Log likelihood = -260.67815 Prob > chi2 = 0.0000

wibs	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
_Igroup_1	-.0435389	.1980956	-0.22	0.826	-.4317992 .3447214
_Itime_1	.2413969	.0964606	2.50	0.012	.0523376 .4304562
_Itime_2	.0071803	.0957329	0.08	0.940	-.1804529 .1948134
_Itime_3	.633952	.0977333	6.49	0.000	.4423983 .8255057
_cons	1.363214	.1564806	8.71	0.000	1.056518 1.66991

For the wibs score (tf>24) the group-time interaction was not statistically significant ($p=0.34$). At baseline the mean wibs score was not significantly different between the two groups (an average of 1.36 for the control group and 1.32 for the intervention group, $p=0.83$ for the group difference). At 6 months this increased by 18% above baseline ($p=0.012$) in both groups, was only marginally, and not significantly higher than baseline (<1%, $p=0.94$) at 12 months, but rose again to 47% above baseline at 18 months ($p<0.001$). The non-linear variation in wibs scores post baseline was statistically significant ($p<0.001$).

Formed in 1988, The ExtraCare Charitable Trust is pioneering new and innovative approaches to improving the health, well-being and quality of life of older people.

Our approach is founded on the principle that factors such as age, health or wealth should not be a barrier to achieving an enjoyable quality of life in old age. We currently operate 28 ExtraCare housing schemes and villages across the Midlands and are the UK's leading creator of mixed tenure village style communities.

The Enriched Opportunities Programme represents the culmination of a decade of practice based innovation, research and development, in partnership with Professor Dawn Brooker and her team at the University of Bradford, into new ways of supporting residents living with dementia and other mental health problems in our villages and housing schemes.

As a model of person centred practice the Enriched Opportunities Programme has many lessons that will be useful in the implementation of the National Dementia Strategy.



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