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Interrogating the Ethics of Telecare Services: A Conceptual Framework for Dementia Home Care Professionals

Patrick Gerard Horgan 9802215.

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Abstract

Professionals working with older people in dementia home care are likely to encounter an increasing range of assistive technological services such as Telecare, as part of the evolving menu of domiciliary care services. These innovations are presenting ethical opportunities and challenges, not fully addressed in the literature to date. This Thesis therefore proposes a conceptual framework for interrogating the ethics of Telecare services, aimed at dementia home care professionals who work with older people. To this end, the Thesis draws on the available evidence base on Telecare service impacts, small-scale foresight studies from actual and potential service users of Telecare and the author's own experiences as a 'Telecare Operator'.

This Thesis acknowledges that the existing literature on 'stand alone' assistive technologies in dementia support, offers well attested recommendations for person-centred design as an essential ethical baseline for networked socio-technical services. As a result, the Thesis recognises that carefully designed Telecare services can be empirically and ethically defended as enabling safer and more sustainable independent living for the cognitively impaired. Yet, the Thesis also addresses the associated ethical concerns that Telecare’s constitutive automatic and monitoring technologies may be generating novel forms of psycho-social risk. Of all such putative risks of the 'panoptic gaze' of Telecare for dementia, the greatest may be the reduction or full displacement of human care in quantity and quality. This Thesis therefore pays considerable attention to how Telecare services might impact on the care dynamics between older service users with dementia and their carers. Given the increasing need for formal and informal care that progressive dementia is understood to present, the Thesis makes a strong ethical appeal that Telecare services alone are not appropriate for all cases of dementia though it is recognised that much more empirical work needs to be done on this question. Neither can Telecare services, even if optimally effective, compensate for frequently criticised deficiencies in the surrounding formal care system for older people with dementia at home and lack of support for their informal carers. Dementia home care professionals are therefore cautioned that Telecare services might be serving social policy goals of rationalisation rather than 'person centred care' at home, seriously compromising the progressive ethos of the 'new culture' of dementia care.

Nevertheless, given the anticipated shortfalls in care provision for a growing older population, it seems that Telecare services are inevitably going to expand and evolve as part of the home care 'mix'. Already the literature attests that Telecare can generate valuable assessment and review data for ongoing 'person centred care' management in home-based dementia situations. Furthermore, current Telecare programmes seem to be facilitating new synergies for formal service partnerships, with major ethical implications for dementia home care professionals working with older people. As matters of significant ethical import, this Thesis therefore pays much attention to the effective coupling of rapid response services with efficient call handling procedures by Telecare Response Centres, the management of carefully designed 'Response Protocols' for a range of personal and domestic crises as well as the legal implications of Telecare data governance, as currently understood.
# TABLE OF CONTENTS

## CHAPTER 1

1.1 Rationale for this study ................................................................. 8
1.2 The field of dementia home care: Relevant Background Considerations ... 10
1.3 A brief preview of the Ethical Contours of this study .......................... 11

## CHAPTER 2 ...................................................................................... 15

2.1 Definitions of Telecare .................................................................... 15
2.2 How Telecare Technologies Relate to Other Electronic Assistive Technologies ................................. 17
2.3 Telecare as Evolution of the Community Alarm System ................. 19
2.4 The Current UK Model of Telecare ................................................ 20
2.4.1 The Domestic Infrastructure of Telecare ..................................... 20
2.4.2 The Social infrastructure of Telecare ......................................... 22
2.5 Exploring Telecare for People with Dementia .................................. 23
2.6 Example of a Technological Support package for Someone with Dementia ........................................ 26
2.7 The Current Evidence Base for Telecare for People with Dementia .... 27
2.8 Policy Support for Telecare in General ......................................... 29

## CHAPTER 3 ...................................................................................... 32

3.1 Exploring Old and New Cultures of Dementia care ......................... 32
3.1.1 Valuing people with dementia and those who care for them .......... 36
3.1.2 Treating people as individuals .................................................... 38
3.1.3 Looking at the world from the perspective of people with dementia ... 38
3.1.4 A positive social environment to enable the person with dementia to achieve well being. . . . . . . 38
3.2 The Significance of Informal Care for Older People with Dementia .... 39
3.2.1 The special case of co-resident carers ...................................... 41
3.3 The Significance of Formal Care for Older People with Dementia ....... 42
3.4 Between Two Cultures of Dementia Care? ..................................... 43
3.5 The Value of Home for People with Dementia ............................... 46

## CHAPTER 4 ...................................................................................... 50

4.1 QUESTION 1: TO WHAT EXTENT ARE TELECARE SERVICES FACILITATING THE HARMONISATION OF ‘PERSON CENTRED CARE’ WITH ‘USER CENTRED DESIGN’ IN DEMENTIA HOME CARE? ........................................... 52

4.1.1 Do we need any assistive technology or Telecare in the first place in dementia home care? .......... 53
4.1.2 The ethical contours of dementia-friendly home care services ....... 55
4.1.3 ‘Other Centred Design’ or ‘User Centred Design’: Who really benefits? ..................62
4.1.4 The Ethical Case for User Centred Telecare design ..............................................65
4.1.5 Examples: Ethical Dimensions of User Centred Design for People with Dementia .......66
Example 1: ENABLE ........................................................................................................66
Example 2: ‘At Home with AT’ .......................................................................................68
Example 3: Combining Telecare with other Assistive Technologies: The ‘Safe At Home’
Project for People with Dementia ....................................................................................70
4.1.6 Going beyond the available evidence base for Telecare and dementia: Further Ethical
questions ..........................................................................................................................71

4.2 QUESTION 2: TO WHAT EXTENT ARE TELECARE SERVICES OFFERING
ENABLEMENT OR CONTAINMENT FOR PEOPLE WITH DEMENTIA AT HOME? ......73
  4.2.1 Telecare Services and empowerment at home ......................................................75
  4.2.2 The case for technologically enabled rehabilitation for people with dementia ..........76
  4.2.3 Telecare, home safety and risk for people with dementia ......................................78
  4.2.4 Risk and dementia care .......................................................................................80
  4.2.5. Telecare services as creating new forms of risk? ................................................83
  4.2.6 Example 4: Ethical issues around Telecare and ‘wandering’ .................................93
  4.2.7 Balancing Enablement of people with dementia with their need for care ..................96

4.3 QUESTION 3: HOW ARE TELECARE SERVICES IMPACTING ON THE
RELATIONSHIP BETWEEN THE PERSON WITH DEMENTIA AND SIGNIFICANT
OTHERS, PARTICULARLY INFORMAL AND FORMAL CARERS? .................................98
  4.3.1 Informal Carers and Telecare .................................................................................98
  4.3.1.1 Additional ethical issues for shared home users ................................................101
  4.3.2 Telecare and Formal Carers ..................................................................................101
  4.3.3 Common ethical issues for informal and formal care: ‘High tech’ versus ‘high touch’ .104
  4.3.4 Ethical and Legal limitations on 'high-tech' developments relevant to dementia home care. 105
  4.3.5 Example 5: Smart homes for people with dementia. ...........................................108
  4.3.5.1 Designing the Gloucester Smart House as a dementia-friendly environment .........110
  4.3.5.2 Ethical issues in dementia support raised by the Gloucester Smart House and similar
models ............................................................................................................................114
  4.3.6 Smart Housing Applications and the link to Telecare services ...............................116

4.4 QUESTION 4: WHAT ARE THE ETHICAL IMPLICATIONS OF THE FORMAL
SERVICE RE-CONFIGURATIONS THAT TELECARE IS INTRODUCING? ..................117
  4.4.1 The quality of the Telecare ‘Social Response’ .......................................................118
  4.4.1.1 Telecare Service providers and other business ....................................................118
  4.4.1.2 Coordinating a rapid social response .................................................................120
<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.4.2 Telecare services, data protection and 'response protocols'</td>
<td>121</td>
</tr>
<tr>
<td>4.4.2.1 Data protection and Telecare Response Protocols</td>
<td>123</td>
</tr>
<tr>
<td>4.4.2.2 Data Integrity in Telecare Services</td>
<td>126</td>
</tr>
<tr>
<td>4.4.3 Telecare's interactions with the wider formal care system</td>
<td>127</td>
</tr>
<tr>
<td>4.4.3.1 Telecare data for Community Care Assessment</td>
<td>127</td>
</tr>
<tr>
<td>4.4.3.2 The Interaction of Telecare with other ICT Trends for People with Dementia</td>
<td>129</td>
</tr>
<tr>
<td>4.4.3.3 Telecare in the context of more older &amp; dementia–friendly services</td>
<td>130</td>
</tr>
<tr>
<td>4.4.3.4 Example 6: Current ethical challenges suggested by Telecare implementation in England</td>
<td>132</td>
</tr>
<tr>
<td>4.4.3.5 Example 7. Author's Own Practice: Are Telecare services really appropriate for some forms of dementia?</td>
<td>135</td>
</tr>
</tbody>
</table>

CHAPTER 5 ..................................................................................................................... 138

BIBLIOGRAPHY .................................................................................................................. 144
### Table of Figures

<table>
<thead>
<tr>
<th>Figure Number</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1: The inter-relationship between Telecare and other electronic assistive technologies.</td>
<td>18</td>
</tr>
<tr>
<td>Figure 2: Three Generations of Telecare</td>
<td>20</td>
</tr>
<tr>
<td>Figure 3: The Domestic Infrastructure of Telecare.</td>
<td>21</td>
</tr>
<tr>
<td>Figure 4: The Social Infrastructure of Telecare</td>
<td>22</td>
</tr>
<tr>
<td>Figure 5: The interaction of the 4 main components of Telecare</td>
<td>23</td>
</tr>
<tr>
<td>Figure 6: Example of a technological support package for someone with dementia</td>
<td>27</td>
</tr>
<tr>
<td>Figure 7: Summary of Evidence on Telecare Services so far</td>
<td>28</td>
</tr>
<tr>
<td>Figure 8: Some policy initiatives on ‘Electronic Assistive Technology’ (EAT) and Telecare support in the UK.</td>
<td>31</td>
</tr>
<tr>
<td>Figure 9: Thematic outline of Chapter 4</td>
<td>51-52</td>
</tr>
<tr>
<td>Figure 10: Thematic Outline of Question 1</td>
<td>53</td>
</tr>
<tr>
<td>Figure 11: The place of Telecare in holistic care planning</td>
<td>55</td>
</tr>
<tr>
<td>Figure 12: Devices used in the ENABLE project.</td>
<td>67</td>
</tr>
<tr>
<td>Figure 13: Devices used in the ‘At Home with AT’ project.</td>
<td>69</td>
</tr>
<tr>
<td>Figure 14: Contrasting possibilities about the ethical impact of Telecare services on people with dementia.</td>
<td>74</td>
</tr>
<tr>
<td>Figure 15: An illustration of creeping surveillance.</td>
<td>90</td>
</tr>
<tr>
<td>Figure 16: An outline of ethical issues relating to Telecare services and informal/formal care</td>
<td>98</td>
</tr>
<tr>
<td>Figure 17: Possible Service Outcomes Of Telecare Services For Informal Carers</td>
<td>99</td>
</tr>
<tr>
<td>Figure 18: Balancing high tech and high touch?</td>
<td>104</td>
</tr>
<tr>
<td>Figure 19: Designing the sequence of Carer emulation in the Gloucester Smart House</td>
<td>111</td>
</tr>
<tr>
<td>Figure 20: Translating carer intervention into computerized algorithms for water safety</td>
<td>112</td>
</tr>
<tr>
<td>Figure 21: Night Safety System for service user with dementia.</td>
<td>113</td>
</tr>
<tr>
<td>Figure 22: Sample Telecare plan for a home based service user with dementia.</td>
<td>125-126</td>
</tr>
<tr>
<td>Figure 23: Table outlining how Telecare data might feed into an ongoing home care plan.</td>
<td>128</td>
</tr>
</tbody>
</table>
INTERROGATING THE ETHICS OF TELECARE SERVICES: A CONCEPTUAL FRAMEWORK FOR DEMENTIA HOME CARE PROFESSIONALS.

CHAPTER 1

Introduction

An increasing range of care professionals now work alongside people with dementia in managing home-based packages of care, often through partnerships such as Community Mental Health Teams. Such professionals include Social workers, Care Managers, Community Psychiatric Nurses, District Nurses, Housing Support Professionals, Occupational Therapists, Assistive Technology Specialists and a range of home healthcare practitioners, referred to in the body of this Thesis as DHC (Dementia Home Care) Professionals. Such personnel will increasingly be involved in commissioning assistive technological services for home care packages including stand alone devices and increasingly, the networked assistive technological services known as Telecare. For the purposes of this Thesis, such Telecare services are not merely home telephones with automatic sensors. Instead they are treated as multi-stakeholder socio-technical systems with significant ethical ramifications for people with dementia at home and the range of actors who support them.

In Scotland, the ‘Scottish Telecare Programme Board’ is coordinating the ‘Telecare Strategy 2008-2010’ with the policy goal of having 9000 Telecare connections for people with dementia in place by 2010 (Joint Improvement Team, 2008a). But if Telecare services are to work effectively for the benefit of service users with dementia and their carers, there is urgent need for critical ethical reflection on the ideal service design. The outcome of such critique should help DHC professionals to navigate the assistive technological field with confidence, propose customised specifications for ‘person centred care’, and hopefully steer fledgling Telecare services in a dementia-friendly direction.
Accordingly, the overall purpose of this Thesis is to furnish DHC professionals with a conceptual framework to underpin ethical reflection and practice in the field of Telecare services for people with dementia. To this end, the study is framed in terms of 4 main questions:

Question 1: To what extent are Telecare services facilitating the harmonisation of 'person centred care' with 'user centred design' in dementia home care?

Question 2: To what extent are Telecare services offering enablement or containment for people with dementia at home?

Question 3: How are Telecare services impacting on the inter-relationships between the person with dementia and significant others, particularly informal and formal ‘carers’.

Question 4: What are the ethical implications of the formal service re-configurations that Telecare is introducing?

1.1 Rationale for this study

Why do DHC professionals need to reflect on the ethics of Telecare for people with dementia in the first place? At the risk of stating the obvious, all interactions with vulnerable service users are moral encounters so that ethical concerns will pervade dementia support whether assistive technologies are used or not. Therefore part of the health and social care professional ethos is to continually reflect on the moral dimensions of practice where,

'... a concern with Ethics is not about adding something to technical problems... but rather is about drawing out an inherent facet of practice... making explicit that which is implicit... Thus members of the caring professions must be able to explain moral choices and explain these in moral terms' (Hugman, 2005: 29).

New models of home support, enabled by Information and Communications Technology (ICT), should therefore be no exception to ongoing professional ethical critique since ICT applications are often seen to be reconfiguring and ‘revolutionising’ healthcare delivery (Fieschi, 2002; Finch et al., 2008). The emergence of home Telecare can be seen as part of this larger trend. Telecare operates through networks of home-based technologies which are linked to response agents via a Telecare Response Centre (Telecare Services Association, 2006). This Response Centre can activate rapid responses to direct request for help or to automatic signals from home-based ‘smart sensors’, which are pre-programmed for specific personal safety, health and home security risks. Telecare therefore operates as a service of networked smart and assistive technologies, closely aligned to chains of rapid response personnel. DHC Professionals, who are considering the commissioning of Telecare services for people with dementia, need to take this full socio-technical ‘ecology’ into account. It is therefore the ethics of the service configurations of Telecare and not so much the technological
characteristics of its component technologies that is the primary focus of this Thesis.

From the start, any ethical consideration of Telecare and dementia can only be understood by looking at the acceptability and appropriateness of Assistive Technology for people with dementia in general. In line with good practice in dementia home care, the UK Alzheimer's Society has stated that,

'Assistive technology(AT) can allow people with dementia to live independently and remain in their own homes for longer than would otherwise be possible ...Health and social care organisations should ensure that evidence-based assistive technology is available to help people with dementia maintain their independence and dignity' (Alzheimer's Society, 2006:1).

There is an increasingly plausible case that assistive technological services can contribute to the emerging 'new culture' (Kitwood, 1997) of dementia support. In particular, purpose-designed stand alone 'Electronic Assistive Technologies' (EAT) for dementia users and their carers, have been positively evaluated by projects such as ASTRID (Marshall, 2000) and ENABLE (Bjorneby et al., 2004; Cash, 2004; 2006). Such studies have contributed to the growing evidence-base that customised EAT can enable people with dementia to 'stay put' at home by averting or delaying institutional care. This strong ethical support from stand alone studies may be transferable to networked socio –technical services, but only if Telecare developments are subject to the same critical scrutiny as their non-networked predecessors. However, Telecare services pose additional ethical questions which need further empirical work and deliberation.

Yet, an overall paucity of empirical investigation is observable to date. Whatever research exists pays insufficient attention to ethical questions for vulnerable end-users. In relation to home monitoring technologies in particular, Mahoney et al., (2007:219) note,

'Most previous research on home monitoring technology has focused on the effectiveness of the interventions, and very little of it specifically addresses the ethical issues in research or in routine clinical practice ...'

It is therefore not surprising that the rapid roll-out of Telecare services in the UK is attended by calls for more ethical debate:

'As the technology develops, we need a debate about the moral and ethical issues around the use of technology, incorporating debate on the best way to ensure that basic human rights are respected by the introduction of new technology' (Help the Aged, 2007:6).

The need for more research and debate on Telecare services is coupled with calls for ethical guidelines to oversee good practice in this field, particularly for vulnerable groups like people with dementia and their carers (Woolham et al., 2007; Botsis & Hartvigsen, 2008; Martin, 2007). But
before we can produce such guidelines we need far more empirical work, as pointed out by Marshall (2000):

‘We need more experience of using technology in practice as well as more attention to wide ethical issues in dementia care before comprehensive and definitive ethical guidelines can be prepared’ (op. cit., 40).

To this end, a research project has recently been launched in the UK - 'Ethical Frameworks for Telecare Technologies for older people at home' (EFORTT) (Mort, 2009), but no results are yet available. Although the findings of this Thesis are limited by the paucity of relevant empirical material available, it is able to draw on a number of pilot and small-scale Telecare studies, some foresight studies on possible future impacts of Telecare and the author's own reflective practice as a Telecare Operator, to address the 4 Study Questions.

### 1.2 The field of dementia home care: Relevant Background Considerations

In designing any home care package, the DHC professional has to draw on the best available baseline knowledge of dementia and the service models available for its optimal ethical support.

In line with an ageing UK population, the proportion of people with dementia is expected to reach an estimated 1 million people by 2025 (Alzheimer’s Society, 2007a). Dementia is regarded as the most expensive condition that health and social service providers face in the UK, constituting a growing public health challenge. Because dementia affects mainly older people, ethical questions about ageing are highly significant to the DHC professional assessing home care needs. Despite the questionable moral tone surrounding ‘Burden of Ageing’ discourses and terms such as ‘Silver Tsunami’ (Gee, 2008a), it cannot be denied that the ‘dependency ratio’ in the UK and other developing economies is increasing, with serious resource implications for the future. This is because older people are the primary users of health and social services in the UK (Loader et al., 2007), with people over 65 occupying almost two-thirds of general and acute hospital beds (Laviolette & Hanson, 2007). In addition, there is a clear correlation between healthcare dependency and ageing with four times as many people aged 85+ years needing daily care compared to those aged 65-74 years (Botsis & Hartvigsen, 2008). The consequent resource implications coupled with the ethical desire for improvements in 'person centred care', are continually challenging service providers with the ‘holy grail …of improved quality at lower cost’ (Kinder, 2003:5). There is a resultant quest for better home support models for various groups with complex needs. As part of this trend, the DHC professional will be aware that arguments for the
cost effectiveness and service quality-effectiveness of home care models compared to institutional models for vulnerable older people are increasingly being advanced (Audit Commission, 2004a). For example, it is estimated that supporting a chronically unwell person at home with intensive home care is half the cost of a residential place, a quarter of a nursing home place and an eight of providing care in a hospital (Fisk, 2003). Because almost two thirds of the known dementia population in the UK are living in the community (Alzheimer's Society, 2007a), the goals of ‘staying put’ and ‘ageing in place’ are becoming more realisable through the ‘person centred design’ of customised home care packages involving formal care, partnership working with informal carers, housing support, and assisted self-care with possible Telecare overlay. But despite such service developments in ‘person centred care’, the field of dementia care still seems riven by tensions between ‘old culture’ and ‘new culture’ concepts and practices (Marshall & Tibbs, 2006). ‘Old culture’ practices emphasise the medicalisation of dementia, with biases towards institutional forms of care and the containment of risk. ‘New Culture’ practices in contrast, influenced by the ‘social model of disability’, focus on ‘person centred care’ in partnership with other stakeholders such as informal carers and carefully designed socio-technical environments (Stokes, 2002). In a sense, we now live between two cultures of dementia care. The ethical impacts of Telecare have therefore to be considered within this dialectic. In considering any commissioning of Telecare, the DHC professional will therefore appreciate that such services may contribute to the ‘new paradigm’ (Hunter, 1997) of dementia care or reinforce/reintroduce some ‘old culture’ practices by stealth. As an exploratory preview, the following section presents a brief glimpse of the ethical contours of Telecare services for dementia, in advance of their fuller treatment in the body of the Thesis.

1.3 A brief preview of the Ethical Contours of this study

A brief conceptual soupçon of each study question now follows.

Question 1: To what extent are Telecare services facilitating the harmonisation of ‘person centred care’ with ‘user centred design’ in dementia home support?

There seems to be a natural affinity between ‘person centred care’, and ‘user centred design’ in the assistive technology literature. Excellent practice examples already exist in the stand alone assistive technological literature for dementia. Yet, there are legitimate doubts about the achievements of person centred design in Telecare implementation to date, which would satisfy the ethical benchmarks of ‘person centred care’ in dementia. This is because the key drivers of Telecare
services may often be suppliers, formal and informal carers with little attention given to the voice of people with dementia themselves (Astell, 2006). Yet, although much empirical work remains to be done on the ‘dementia-friendliness’ of Telecare services, it is still possible to provide some early speculative commentary as provided in Chapter 4 of this Thesis.

**Question 2: To what extent are Telecare services offering enablement or containment to people with dementia at home?**

‘Respect for autonomy’ is fundamental to the ethical frameworks used in healthcare such as that of Beauchamp and Childress (2001) and in social work generally (Clark, 2000; Banks, 2000). But dementia presents unique challenges for promoting autonomy, if the illness/disability is compromised by the gradual erosion of cognitive capacity.

By safeguarding routine domestic activities, Telecare services could enhance the enablement of the estimated 6% or so of people with dementia who are independent and do not need any services (Alzheimer Scotland, 2007). There could be further enablement benefits for ‘low interval' service users. For example, Telecare 'solutions' (Tunstall, 2007) can enable the retention of cooking skills and the safe execution of various activities of daily living. As a dementia condition advances, Telecare services can provide a rapid alert and alarm function for various home hazards and personal risk, provided rapid response services are available. Yet, there are ethical dangers that Telecare will create a predominantly ‘containment model’ for people with dementia, with a more holistic view of the person marginalised by his/her computer generated ‘risk profile’. This could be used to justify ‘old culture' practices such as paternalism by stealth and the neo-institutionalising effects of ‘panoptical Telecare’ (Laviolette & Hanson, 2006). Furthermore, the increasing levels of dependency in most dementias create growing risks of inadequate human care. This is because, however sophisticated the substitutability of care by assistive technological services, the latter cannot yet adequately supervise tasks such as personal hygiene, grooming and medication compliance. Some kind of reliable ‘care net’ of informal and formal inputs is therefore an ethical requisite for most cases of progressive dementia, sooner or later.

A thorough attention to such outlined issues for Question 2 will be provided in Chapter 4 of this Thesis.
Question 3: How are Telecare services impacting on the relationships between the person with dementia and significant others, particularly informal and formal 'carers'.

Telecare services may interact recursively with informal and formal care networks and the DHC professional needs to be aware of the dynamic between 'high-tech and high-touch' (Naisbitt, 2001) in technologically-enabled home care packages.

Although ‘supportive technologies’ were anticipated to ease the burden on carers in the English National Strategy for Carers (Department of Health, 1999), there is little empirical evidence to date of such impact. However, it must be said that informal carers’ groups seem to be taking very positive views of the prospects of Telecare services and assistive technology in general (Office of Public Management, 2005; Carers UK, 2008). This seems to be mainly due to its respite and 'peace of mind' benefits for them (Bowes & McColgan, 2006).

Policy sources will continue to assert that new technology has to complement human caring and not substitute for it (Audit Commission, 2004b). But there is justifiable ethical disquiet that Telecare services may lead to the substitution of human caring by stealth, where ICT-enabled care packages remotely manage data based ‘simulacra’ (Baudrillard, 1994) of dementia instead of directly interacting with embodied people. Some of the performance indicators on the putative benefits of Telecare in Scotland, such as reductions in sleepover care and home visiting, even suggest that this trend may be happening already (Joint Improvement Team, 2008b). The possible impact of Telecare services on formal healthcare service reduction or withdrawal therefore requires continuing vigilance by the DHC professional. This may be a particularly crucial ethical issue for people with dementia because of their high relational dependency on informal support (Kitwood, 1997), with associated needs for nurturing psychological and spiritual 'interiority' (Hanvey, 2008).

Further treatment of these issues relating to Question 3 will be provided in Chapter 4 of this Thesis.

Question 4: What are the ethical implications of the formal service re-configurations that Telecare is introducing?

Telecare Response Centres, where operators act on arrays of voice and data signals from Telecare service users, are at the socio-technical core of the Telecare system. The speed and quality of any social or emergency response in cases of dementia, is therefore a vital ethical question for any DHC professional commissioning Telecare services (Alzheimer's Society, 2007b).

Telecare Response centre operation is also structured around carefully negotiated 'protocols'
(Woolham et al., 2007), to maximise user choice and privacy in any anticipated crisis event or emergency. Yet, such protocols frequently present ethical dilemmas in practice and the DHC professional needs to be aware of the challenges of negotiating them effectively with the service users, any advocates and other stakeholders.

The DHC professional will also be increasingly aware of the potential for Telecare service data to contribute to 'Single Shared Assessment' and home care package reviews (Price, 2007a, b). The literature notes that the ‘synergy’ of inter-professional partnership is vital to the efficacy of Telecare services (Audit Commission, 2004b; Barlow et al., 2003). Yet, despite the West Lothian attestations of this (Bowes & McColgan, 2006), the barriers of multi-disciplinary and inter-professional working are seen as a stumbling block in the implementation of Telecare in some parts of England (Woolham et al., 2007). Hence, the DHC professional will appreciate that Telecare services are not immune from the difficulties in inter-professional and inter-organisational working, observed elsewhere in the literature (Dalley, 1993; Glasby, 2007).

However, a more serious barrier to the effective implementation of Telecare services may be the quality of the formal service surround, with conventional home care services for older people frequently criticised as deficient and unsatisfactory (Curtice et al., 2002). However effective Telecare services might prove in their own right, this may not be enough to compensate for generally perceived unsatisfactory home care services for older people with dementia (Alzheimer Scotland, 2008).

The issues relating to the interaction between Telecare and the formal service surround will be thoroughly examined in Chapter 4 of this Thesis.

Finally, it is clear that much more empirical work needs to be done on the ethical impact of Telecare services as a complex socio-technical innovation. In the meantime, this Thesis deliberates on the issues, using studies of stand alone technology, speculative studies of Telecare in the general literature and reflections on the author's own experience as a Telecare Operator. Despite the paucity of empirical work to date on the ethics of Telecare for the home care of people with dementia, it is hoped this Thesis will make an initial contribution to reflective practice by DHC professionals in this field.
CHAPTER 2

OVERVIEW OF TELECARE AS A SOCIO-TECHNICAL SERVICE FOR HOME BASED PEOPLE WITH DEMENTIA.

The aim of this Chapter is to give an outline of current understandings of Telecare services. The emphasis throughout is on Telecare as a socio-technical system involving human agents with clearly assigned roles as well as networked assistive technologies. It should provide Dementia home care (DHC) professionals with sufficient material to successfully navigate the current Telecare landscape, in advance of the full ethical analysis in Chapter 4 of this Thesis.

2.1 Definitions of Telecare

Telecare or ‘care at a distance’ has been generally defined as,

‘The remote or enhanced delivery of health and social care services to people in their own homes by means of Telecommunications and computer based systems’ (Barnes cited in Brownsell & Bradley, 2003).

It is important to note two main Telecare trends in practice which will influence any working definition:

1. The increasing development of ‘Telehealth’ applications converging with the Telecare domain of home safety monitoring;
2. The emphasis on Telecare as a socio-technical system, since the effectiveness of the technology is highly conditional on an effective human response.

Firstly, it is acknowledged that most authors make a conceptual distinction between ‘Telemedicine’ and Telecare where,

‘[Telemedicine] is a medical intervention using technology and virtual presence to assist in the remote diagnosis and support of medical conditions, whereas telecare is about support and monitoring of activities in the home ’ (Dewsbury 2007a:4).

Although the distinction between Telecare and Telehealth was very marked when both modes were first developing in the 1990s, there is now increasing convergence between the various ‘Tele’ modes of delivery in health and social care services. For vulnerable service users, these increasingly incorporate medical ‘vital signs’ as well as home safety monitoring. To accommodate such practical
trends, an increasingly relevant definition is therefore:

'Telecare is the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living' (Hards, 2006:1).

For the purposes of this Thesis, the term Telecare is therefore used to encompass health as well as social care modes of delivery, as this is how Telecare will be increasingly experienced by users with dementia in practice. As a home-focused ICT innovation, Telecare also seems set to converge with other online information services (Siotia & Simpson, 2008). This anticipated ICT horizon is significantly relevant for people with dementia and their carers, who would seem to benefit from a ‘one stop shop’ approach to information and advice services.

Secondly, it has frequently been emphasized that Telecare is a socio-technical system highly dependent on the orchestration of human support services where,

'Telecare can be seen as a new method of service delivery, supported by new technology and existing technology used in new ways’ (Barlow et al., 2007:178).

For the purpose of this Thesis, Telecare is therefore understood to be a socio-technical support service, linking home-networked ‘Electronic Assistive Technologies' to a ‘Telecare Response Centre’ which activates an appropriate ‘social response’ to any request for help. The Response Centre can be contacted directly by the service user or is alerted by automatic signals from smart sensors programmed to detect specific domestic events such as floods, fire, intrusion etc. In an increasing minority of cases, Telecare services may also be configured to provide a direct link between home technologies and informal carers, as in some 'lifestyle monitoring' systems (Price, 2007a, b).

It is worth noting that other terms are also used in the literature in relation to sophisticated Telecare applications. The term ‘Ambient Assisted Living’ (AAL, 2007) is often used in Europe for general applications and the dementia-specific ‘Every Day Technologies for Alzheimer's Care' (ETAC, 2009; Dishman & Carrillo, 2007) in the USA. In the UK, there is also the ‘Smart and Aware Pervasive Healthcare Environment’ (SAPHE) programme (Imperial College, 2008) and the Scottish university collaboration called ‘Mobilising Advanced Technologies for Care at Home (MATCH, 2007).

However, the terms ‘Telecare', 'Telehealth', 'Electronic Assistive Technology' and ‘Smart (Home) Technology' seem to be used in most of the research and policy literatures surveyed to date and thus constitute the terminology used in this Thesis.
2.2 How Telecare Technologies Relate To Other Electronic Assistive Technologies.

Assistive Technology (AT) is an umbrella term describing,

‘...services and systems that allow a person to accomplish a task they would otherwise be unable to do or increases the ease and safety with which the task can be performed’ (Royal Commission on Long Term Care (1999) cited in Marshall & Tibbs, 2006:148).

Networked technologies are part of a growing suite of electronic assistive and environmental control technologies. In discussing electronic assistive technologies, Marshall & Tibbs (2006:148) outline three categories as follows:

1. **One off items** (These can also be termed non-networked or stand alone items);
2. **Items that activate something else** (These are often called ‘smart home technologies’ allowing devices to interconnect for the purposes of home safety or user enablement);
3. **Items connected to the Telephone system (sometimes called Telecare).**

From a survey of the literature to date, most of the empirical research seems to be on **Category 1 technologies** (e.g. ASTRID (Marshall, 2000), ENABLE (Bjorneby et al., 2004; Gilliard & Hagen, 2004) and AT HOME WITH AT (Cash, 2004; 2006)). This has produced a very rich platform of support for AT benefits to people with dementia and their carers, with valuable lessons apparently transferable to networked socio-technical systems such as Telecare.

To a lesser extent, there are prototypical evaluations of **Category 2 systems** such as the ‘Gloucester Smart House’ (Orpwood et al., 2005) and the ‘Alzheimer’s House’ (Serna et al., 2007). Originally Smart Houses were designed around home safety and comfort for a general needs sector, with considerable market growth still observable (Pragnell et al., 1999). In addition, smart home technologies have been developed for people with physical disabilities to complement barrier free mobility. In relation to older people in general, the European Commission in its recent ‘**Action Plan on ICT and Ageing**’, sees a tripling in the market for smart home applications between now and 2020 (Commission of the European Communities, 2007), though its action plan does not specifically mention specialist applications for dementia support.

The focus of this Thesis is on **Category 3 technologies**, as part of **Telecare services**. A thematic outline of how the three categories interrelate is presented as follows:
Figure 1: The inter-relationship between Telecare and other electronic assistive technologies.

<table>
<thead>
<tr>
<th>SOCIO TECHNICAL CATEGORIES</th>
<th>EXAMPLES OF DESIGN MODELS</th>
<th>PRACTICE EXAMPLES.</th>
<th>IMPLICATIONS FOR PEOPLE WITH DEMENTIA AND THEIR INFORMAL CARERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. NON NETWORKED TECHNOLOGIES</td>
<td>1. ENABLE (Gilliard, &amp; Hagen, 2004).&lt;br&gt;2. AT HOME WITH AT (Cash, 2004).&lt;br&gt;Both suites of technology have 3 main functions: &lt;br&gt;- Communication &lt;br&gt;- Prompting and Reminding &lt;br&gt;- Home Safety&lt;br&gt;CIRCA (Astell, 2006) is multimedia software with touch screen interface to enable reminiscence work.</td>
<td>Most devices are now commercially available and catalogued through AT DEMENTIA (AT DEMENTIA, 2009) and TELECARE MADE EASY (2009).&lt;br&gt;Not yet commercially available.</td>
<td>Very similar findings from research results in both cases of ENABLE and AT HOME WITH AT:&lt;br&gt;- Preference for empowering user with dementia, as far as possible.&lt;br&gt;- In practice, much carer support is needed for best effect.&lt;br&gt;- Devices work best with early – mild dementia, when there is potential for further learning and rehabilitation.</td>
</tr>
<tr>
<td>2. SMART HOME TECHNOLOGIES</td>
<td>GLOUCESTER SMART HOUSE (Orpwood et al., 2005).&lt;br&gt;Provides electronic supervision of safely executed activities of daily living, generating alarms or alerts to local carers if necessary.</td>
<td>Smart House is now implemented in Hillview Flats, a supported housing complex used for respite care for people with dementia.</td>
<td>• Emulated Carer design philosophy (Orpwood, 2005).&lt;br&gt;• Smart Houses seem to be working best when embedded in Sheltered Housing or Housing with Care schemes (Dementia Voice, 2007).</td>
</tr>
<tr>
<td>3. TELECARE SYSTEMS.</td>
<td>Northamptonshire 'Safe At Home' project. (Woolham, 2006).&lt;br&gt;West Lothian 'Home Safety Service' (Bowes &amp; McCollgan, 2006).</td>
<td>Nothamptonshire is a specialised dementia service.&lt;br&gt;West Lothian is a mainstream service for older people. Both projects include 'dementia friendly' 'solutions' for safe cooking, wandering, night safety etc. which can reduce risks of independent living.</td>
<td></td>
</tr>
</tbody>
</table>
Telecare has grown out of a Community Alarm platform which was initiated in post-war Sheltered Housing Schemes. Currently, it is estimated that about 1.6 million people in Britain have connections to a Community Alarm system with about 500,000 of these living in Sheltered Housing. In effect, most Sheltered Housing can be understood to have delivered ‘First Generation Telecare’ to its residents (Brownsell & Bradley, 2003). Here, users contact an on-site Warden/Scheme Manager through pull-cord or pendant alarms. During staff ‘on call’ or off duty time, signals are relayed to a Telecare Response Centre (Telecare Services Association, 2006) where Operators provide reassurance and assistance, and can contact emergency services or nominated contacts. However such ‘1st generation’ Telecare systems have to be activated by the home user and have no inherent ‘smart’ function. They are therefore only of limited use for some people with dementia who may not be able to use them or even known they exist in the first place (Doughty et al., 2004).

As an improvement on such limitations, we are now witnessing the 2nd generation of Telecare where the Community alarm infrastructure is enhanced through ‘smart’ monitoring sensors for a range of personal risks and home hazards. This means that more critical incidents are detectable because they are event-activated as well as user-activated (Siotia & Simpson, 2008).

Both 1st and 2nd Generation Telecare systems can be referred to as ‘response mode’ or r-mode Telecare so that critical events can be monitored and rapidly responded too. In tandem with increasing policy attention to preventive health, there is growing development in ‘3rd Generation’ or ‘proactive mode’ (p mode) Telecare. Such applications can continuously monitor activities of daily living to flag up potential difficulties in coping or early warnings of health difficulties (Audit Commission, 2004b). Significantly, these technologies could have particular utility for someone with dementia who is unable to observe or articulate any decline in his/her daily functioning or health, as suggested by the following observation:

'More advanced ‘intelligent’ systems are designed to recognise changes in activity levels, such as visits to the toilet or fridge, which may indicate that a person’s condition is deteriorating. Early targeted interventions can then be implemented, with the emphasis on prevention' (Wanless, 2006:155).

The conceptualisation and development of such socio technical ‘generations’ is illustrated as follows:
Generations of telecare

The frequent and practical inter-changeability of terms such as 'smart technology' with Telecare brings us to the question of whether Telecare can always be considered 'smart'. There is some dispute in the literature about this definitional and practical issue (e.g. Dewsbury, 2007b). The argument that Telecare is not 'smart' seems increasingly pedantic; it is noteworthy that leading Telecare providers are increasingly configuring home sensors to interact in order to manage pre-specified home safety risks such as unsafe cooking. For example, a pre-timed bed absence monitor – to alert a possible fall- will not be triggered if the home user’s movement is detected elsewhere in the house. More such 'smart solutions' (Tunstall, 2007) are likely in the future, subsumed under the generic category of Telecare.

2.4 The Current UK Model of Telecare

2.4.1 The Domestic Infrastructure of Telecare

Standard Telecare seems to be constellating around certain sensors and devices. The following diagram represents the set of technologies that constitute typical Telecare systems in the UK.
The 'pull chord' (top left) or neck pendant (centre left) are the core interfaces with the end user, representing the primary link to the Telecare Response Centre. The 'Movement Detector (PIR)' (top of picture) refers to the 'Passive infra-red detector' for 'inactivity monitoring', based on common practice in Sheltered Housing. This monitor is automatically checked by the Telecare Response Centre at regular time intervals to ensure the resident is active, if known to be at home. Any detected non-movement can then be dealt with by contacting the home user in the first instance, with further escalation to keyholders/carers or emergency services if necessary. Fast -accurate data from the other sensors in the diagram are likewise interpreted by Telecare Operators who can initiate an appropriate course of action to predefined hazards or crisis situations. Most of the sensors
shown are self-explanatory.

In addition, the ‘Temperature Extremes Sensor’ (bottom right corner) detects temperatures above or below a set limit. At the hot end, the detection of rapid rises in heat may be preferable to smoke detectors in kitchens which are often too sensitive. At the cold end, the sensor can flag up the possible risk of hypothermia. This sensor is particularly noteworthy as extreme temperature scenarios may be highly relevant to someone with dementia.

2.4.2 The Social infrastructure of Telecare

Figure 4: The Social Infrastructure of Telecare

Source: Doughty (2005).

The network of possible service providers, formal and informal, is all accessed from the ‘Telecare Control Centre’ (or Response Centre) top left corner. There is frequent reference in the literature to the necessity for a speedy and coordinated ‘social response’ if full benefit is to be derived from
Telecare (Audit Commission, 2004b; Wanless, 2006). Telecare 'response protocols' have to be devised for a range of anticipated contingencies, customised as far as possible to the stated preferences of each service user or their advocates. However, orchestrating an effective social response is proving to be quite challenging for Telecare services and its ethical implications are discussed in Chapter 4 of this Thesis.

2.5 Exploring Telecare for People with Dementia

Barlow's (2006b) general model of Telecare services is proposed in this section, as it seems to have particular applicability to 'new culture' dementia support. This is because the service user is placed at the hub of the service system, with the various socio-technical inputs aligned to promote 'person centred care'. According to this model, Telecare configurations have four interacting components:

- The provision of information and communication to the end-user;
- Monitoring the safety and security of the home environment;
- Monitoring the 'lifestyle' and 'vital signs' of the individual home occupants(s);
- Incorporating 'stand alone' technologies in the assistive technology mix if needed.

This interaction is illustrated in the following diagram:

**Figure 5: The interaction of the 4 main components of Telecare.**

---

Assisted living: telecare applications

- **Safety and security monitoring, e.g.**
  - Bath overflowing, gas left on, door unlocked

- **Prevention**

- **Information & communication, e.g.**
  - Health advice, virtual self-help groups

- **Improving functionality**

- **Electronic assistive technology, e.g.**
  - Environmental controls, doors opening/closing, control of beds

- **The Individual in their home or wider environment**

- **Individual monitoring:**
  - Physiological signs
  - Lifestyle / activities

- **Mitigating risk**
  - Prevention

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TANAKA BUSINESS SCHOOL
This seems a highly plausible model for dementia home support as Telecare services not only involve mitigating domestic risk but ‘improving functionality’ to the end-user. They can therefore be applied for rehabilitation as well as home safety purposes, harmonising with current trends in dementia support (Marshall, 2006). The two additional functions of ‘information and social inclusion’ also seem particularly relevant to the growing phenomenon of ICT-enabled ‘citizenship’ models of dementia (Marshall & Tibbs, 2006).

The provision of information and communication to the end-user

Marshall & Tibbs (2006) note the literature on the reported benefits of ICT to people with dementia. For example, people with dementia who have published biographical accounts have claimed they were able to use a computer after losing pen and paper abilities. In addition, the use of Microsoft PowerPoint can support people with dementia giving presentations at conferences. Email, recorded text messages and telephone recording also seem very useful as memory aids. To promote more digital inclusion across the generations, there is a case for encouraging the retention of ICT skills in future cohorts who can reasonably be expected to be more ICT literate.

Channels of communication for home based people with dementia and their informal carers, such as videoconferencing and online discussion, were demonstrated in the ACTION project (Magnusson & Hanson, 2003). In this ICT support model, people with dementia and their ‘families’ could interact with others through discussion forums and webcams. Overall the project was very successful and is now implemented in parts of Sweden. However, ethical issues about video communication with people with dementia at home need to be further addressed, despite some reported success of home video monitoring projects in promoting medication compliance for dementia care (Smith et al., 2007).

Environmental Monitoring

These are mainly ‘Smart House’ applications, where the main focus is on monitoring the home user’s personal safety and security. Such monitoring has clear advantages over user-activated systems which rely on the home-user initiating contact with a warden or Response Centre via a pendant alarm or pull-cord. Some community alarm studies show that there is poor compliance with
pendant alarm wearing in general and this may be more acute for cognitively frail people (Blyth et al., 2005). Therefore, for some people with dementia, some kind of automatic continuous monitoring seems warranted and the ethical implications of this will be discussed in Chapter 4 of this Thesis.

**Lifestyle and Health Monitoring**

The value of activity and lifestyle monitoring was established from the seminal work of Celler et al. (1995) (Brownsell & Bradley, 2003). They demonstrated how the ongoing health and functional status of older people could be deduced from how they interacted with their home environment in terms of room and furniture occupancy, appliance usage etc. For example,

>'The latest generation of lifestyle reassurance software ... is able to monitors clients' behavioural trends and can detect possible problems, for example decreasing appetite, signalled by less frequent use of electrical appliances such as the kettle, fridge or microwave' (Rice, 2005:2).

For example, Tunstall (2008) has developed interconnected sets of 'virtual sensors' through a lifestyle monitoring product which is sensitively programmed to personal lifestyle variations. For instance, for 'inactivity monitoring', the timer on a 'bed absence' or 'chair absence' sensor will be reset if the user's activity is detected elsewhere in the house. As another example, the 'Just Checking' (Price, 2007a, b) system has various activity 'sensors' around the home yielding a set of 'indicators' which are sent to a password-protected 'Just Checking' web server. A nominated carer can then log in to view an update of the caree's activity pattern:

>'... The carer or relative can log on to the Just Checking website, at any time and using a unique password to protect confidentiality, can view a simple chart of the activity of the person. ... The carer can see when the person:

> got up and went to bed, and whether he/she had a disturbed night;
> visited the kitchen to prepare meals or drinks;
> left the dwelling and for how long' (Purchasing and Supply Agency, 2006: 33).

Such activity profiling by informal carers can give early indications of sleeplessness, poor nutrition or personal hygiene, enabling more proactive and personally tailored help for someone with dementia at home (Doughty, 2008a). For example, some people with dementia can forget
when they have last eaten so meal timing may need to be monitored and prompted. However, accurate interpretation of the 'Just checking' data seems to depend on strong tacit knowledge by the carer of the end user with dementia.

More specific medical data can be monitored by 'Vital signs' technologies such as 'wristcare' (Hyssalo, 2004), allowing the continuous monitoring of blood pressure, cardiac arrhythmia, chronic obstructive and pulmonary disorders (Celler et al., 2003). Such systems can also detect critical health incidents such as hypoglycaemic events or epileptic seizures.

Although Telemedicine and ‘medical Telecare’ services tend to be provided in ‘hospital at home’ set ups for single conditions, they may become more integrated with conventional Telecare in the future. Future developments in ‘proactive’ monitoring (Audit Commission, 2004b) will also mean that early alerts can be provided for imminent health conditions from the analysis of various biomarkers (‘Technology Research for Independent Living’ (TRIL, 2009)), allowing more effective anticipatory support.

Most Telecare services in the UK are currently delivered over the telephone network. The addition of more sophisticated and interconnected sensors to Telecare packages will require increased broadband capacity. This will be aided by the forthcoming roll out of British Telecom’s 21CN network for voice and data transmission (Tunstall, 2008). Other broadband suppliers using cable or wireless transmission are of course expected to compete for market share.

2.6 Example of a Technological Support package for Someone with Dementia.

‘Enhanced packages’ can be configured for various conditions such as dementia. From the West Lothian 'Home Safety' programme (Bowes & McColgan, 2006; West Lothian Council, 2009) some of the technologies which seem to be most relevant for people with dementia are tabulated as follows:
Figure 6: Example of a Telecare support package for someone with dementia.

<table>
<thead>
<tr>
<th>Device Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed occupancy detector*</td>
<td>This device monitors a person's bed occupancy at night and can trigger an alarm via the Home Alert Console according to pre-set exception rules (for example, if a person gets out of bed at night and does not return within a period of (say) 30 minutes.</td>
</tr>
<tr>
<td>'Wandering' detector*</td>
<td>This device monitors a person’s entry/exit door during a pre-set period when the service user may be at risk. If the sensor is triggered, for example, at 2am in the morning, a carer or the monitoring station would be alerted that the door has been opened.</td>
</tr>
<tr>
<td>Video door entry</td>
<td>An entryphone that has video capability, two way conversation between service user and caller and remote control of door lock by service user. The entryphone has a video output and it can be connected to a TV so that the caller’s face can be viewed on a larger screen.</td>
</tr>
<tr>
<td>Automatic control of lighting</td>
<td>Lighting can be switched automatically by an activator such as when a person gets out of bed at night to light the way to the toilet and then to automatically switch off the lights on return to bed.</td>
</tr>
<tr>
<td>Monitor activities of daily living to assess a person at risk</td>
<td>Sensors can be used to determine the time and frequency of certain everyday activities being carried out and software that can analyse the data to determine if a person is at risk. Sensors might record the use of kitchen appliances such as fridge and kettle, bathroom facilities such as toilet flush and other services in the home such as switching of lighting. The information gathered can identify that a person has departed from their regular routine and is at risk or needs assistance.</td>
</tr>
</tbody>
</table>


2.7 The Current Evidence Base for Telecare for People with Dementia.

In relation to the current general evidence base for Telecare, Barlow et al. (2007) have undertaken a methodologically rigorous review. They found about 6000 published studies, but only 98 were finally selected to meet their stringent quality criteria as follows:

- ‘The selected studies had to be home based Telecare - ‘institutionalized’ settings such as ‘Extra Care Housing’ were excluded.
- They had to include frail elderly people or people of any age with long term conditions.
- They had to be Randomised Trials of any size or observation studies with at least 80 participants’ (op. cit:175)

Of those finally chosen, 67 papers were on ‘information and support systems’, 31 were on ‘monitoring systems’ and only 2 focused on ‘home safety systems’. The latter were the evaluations of the ‘Safe at Home’ (Woolham, 2006a) project for people with dementia, and the West Lothian ‘Home Safety Service’ (Bowes & McColgan, 2006) for older people generally. Apart from these 2
mainstreamed Telecare projects, most of the evidence so far comes from pilot studies and small case studies, so that the evidence base for the effectiveness of Telecare services is still seen as inadequate (Wanless, 2006).

A summary of the evidence of the Barlow et al. (2007) reviews is shown in the following Table:

**Figure 7: Summary of Evidence on Telecare services so far.**

<table>
<thead>
<tr>
<th>Focus of telecare scheme included in systematic review</th>
<th>Evidence on:</th>
<th>Systemic outcomes, i.e. economic impact or impact on processes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual outcomes, i.e. clinical or QOL improvement</td>
<td>Relatively good, growing – numerous individual studies on which to build systematic reviews</td>
<td>Limited, problematic – poor specification of assumptions, lack of robust data</td>
</tr>
<tr>
<td>Specific application, e.g. telecare aimed at patients with diabetes</td>
<td>Largely anecdotal, growing – not yet peer reviewed</td>
<td>Virtually unresearched – based on simulation modelling with limited data</td>
</tr>
<tr>
<td>General application, e.g. aimed at a heterogeneous population ('frail older people')</td>
<td>Largely anecdotal, growing – not yet peer reviewed</td>
<td>Virtually unresearched – based on simulation modelling with limited data</td>
</tr>
</tbody>
</table>

Source: Hendy & Barlow (2008)

- Substantively, the bulk of the most robust evidence for Telecare is in the management of specific clinical conditions. A similar review by Botsis & Hartvigsen (2008) of medical Telecare has found studies demonstrating significant benefits for specific clinical conditions such as diabetes, COPD and wound management. Self-management, health education, feedback and exercise programmes are often a feature of such projects enhancing their success rates, but their interactive demands would seem to compromise their appropriateness and effectiveness for some cognitively impaired people. From these studies 'quality of life' improvements to service users and their carers can also be demonstrated as well as considerable economic benefits. However, the sample sizes are often small so that any qualitative or economic benefits are hard to generalize to larger populations.

- Methodologically, by using randomised controlled trials, it seems far more straightforward to study the effect of Telecare on specific clinical conditions like diabetes, than a more complex illness-disability such as dementia which has wider relational and systemic support...
requirements (Barlow et al., 2007).

If there is very little empirical work on Telecare services generally, there are even less in relation to dementia specifically. This clearly contrasts with the rich vein of literature on non-networked technologies for dementia such as the ENABLE (Bjorneby et al., 2004), CIRCA (Astell, 2006) and INDEPENDENT (Orpwood et al., 2007) projects. It would seem that the only large scale evaluation directly relevant to dementia to date is the Northamptonshire ‘Safe at Home’ project (Woolham, 2006a). The West Lothian ‘Home Safety Service’ (Bowes & McColgan, 2006) though not a specialist service, seems to have a lot to offer people with dementia. However, in the Bowes & McColgan (2006) evaluation, ethical issues are rarely explicitly addressed and the voices of users with dementia seem mainly absent.

Overall, the current ‘evidence gap’ for the effectiveness of Telecare services may be impeding partnerships with medical professionals who require stringent standards of evidence for any health care innovations (Woolham et al., 2007; Hendy & Barlow, 2008). Attention is therefore increasingly drawn to the need to study the systemic aspects of Telecare services (Barlow et al., 2003), since they involve the interaction and alignment of various socio-technical constituencies (Kinder, 2003). Because this task presents considerable methodological challenges, promising developments are the ‘Whole System Long Term Condition Demonstrator Projects’ initiated in April 2008 in England, to examine the large scale effectiveness of ‘Telecare and Telehealth’ as part of integrated health and social care services (Department of Health, 2008).

2.8 Policy Support for Telecare in General

Overall, despite a weak evidence base, expectations that Telecare can provide a range of economic, social and individual preventative health and safety benefits abound in the literature:

‘Users benefit by being able to stay in their homes for longer; the healthcare system benefits by acting in a preventative way and enabling early hospital discharge; government benefits by reduced overall spend; and therefore everyone benefits as taxes are used more efficiently’ (Brownsell & Bradley, 2003).

These claims are supported by growing endorsement by central and local Government and independent ‘think tanks’ on health care and social policy. For example, the highly authoritative ‘Wanless Social Care Review, ‘Securing Good Care for Older People’ (Wanless, 2006) has acknowledged the limitations of the current evidence base, but goes on to argue that there is enough
evidence to suggest that, ‘...Telecare services should shift into the mainstream, despite the difficulty in predicting the impact on costs’.

In relation to dementia care specifically, the applicability of Telecare is well endorsed by the same authority:

‘New models of dementia care will also be important given the projected increase in older people aged 85 and over. The use of dementia-specific care services, including telecare and dedicated housing, together with specialist care workers appears promising’ (Wanless, 2006: xxvi).

At the recent announcement of plans for an English National Dementia Strategy (Department of Health, 2007a), the Health minister Ivan Lewis optimistically places Telecare at the heart of this initiative.

The following Table outlines some of the main policy initiatives in the field of Electronic Assistive Technology and Telecare which seem particularly significant for people with dementia:
Figure 8: Some policy initiatives on Electronic Assistive Technology’ (EAT) and Telecare support in the UK.

UK Policy Papers

with significant mention of EAT/Telecare


Independence, Well being and Choice (Department of Health, 2005).

Securing Good Care for Older People: Taking a long-term view (‘Wanless Social Care Review’) (Wanless, 2006).

Scotland

Scotland: National Telecare Plan (Joint Improvement Team, 2006).

National Telecare Strategy 2008-2010 (Joint Improvement Team, 2008b).

Wales

Wales: Telecare Capital and Revenue Grant (Social Services Improvement Agency, 2007).

Policies and initiatives specifically on EAT/Telecare

England


‘Building Telecare in England’

‘Implementing Telecare’ guidelines

Establishment of special Telecare ‘Learning and Improvement Networks’ (LINs) to provide advice.

Preventative Technology Grant (Total of £80million from 2006 -2008).

Whole System Demonstrator Projects (Department of Health, 2008)


Scotland

Scotland: National Telecare Plan (Joint Improvement Team, 2006).

National Telecare Strategy 2008-2010 (Joint Improvement Team, 2008b).

Wales

Wales: Telecare Capital and Revenue Grant (Social Services Improvement Agency, 2007).
CHAPTER 3

THE CURRENT CONTEXT OF HOME SUPPORT AND TELECARE FOR PEOPLE WITH DEMENTIA

The aim of this Chapter is to highlight for the Dementia home care (DHC) professional the salient aspects of dementia support that should underpin ethical practice in commissioning, implementing and reviewing Telecare services. It pays particular attention to the objective professional understanding and subjective experience of dementia in terms of new and old 'cultures' of dementia care. It then goes on to consider the concept of 'person centred care', pivotal to 'new culture' approaches to dementia. The concept of 'person centred care' is understood to be elastic enough to accommodate relational and systemic dimensions (Adams, 2008a). The Chapter culminates in an exploration of the ethical contours of home as both a site of self-empowerment and as a locus of care for increasing sub-populations of older people. The material in this Chapter therefore sets a context for the ethical analysis of Telecare services in dementia home care in Chapter 4.

3.1 Exploring Old and New Cultures of Dementia care.

Dementia is the name given to a cluster of conditions which impairs the cognitive capacity and functioning of the (usually ageing) brain. It is an acquired syndrome that is 'chronic, progressive and debilitating' (Adams, 2008a: 2). Although usually associated with memory loss, the condition affects wider cognitive function, personal orientation to time and place, personality changes, mood and behaviour disorders. The most common types of dementia are Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies (DLB), Fronto-Temporal Dementia and Picks Disease. Though the underlying neuro-physiologies are different, there is a convergence of symptoms particularly as dementia progresses. In practice, a person can have a 'mixed dementia', usually Alzheimer’s disease and vascular dementia. As a person gets older, other co-morbidities and sensory impairments can compound the condition. Because there is a gradual loss of daily functioning, deterioration of cognitive capacity and emotional control, the progression of the condition usually means an increasing dependence on informal and formal care.

The growth of dementia in ageing populations presents epidemiological and demographic opportunities and challenges for health and social care services. Although there is no 'cure' for most
dementias, the symptomatic alleviation and ‘cognitive boosting’ effects of some medication is increasingly being attested (Adams, 2008). Additionally, even in the medically focused literature, there is increasing focus on the effects of non-pharmacological interventions such as assistive technologies and home-based Telecare services (Douglas et al., 2004; Siotia & Simpson, 2008).

As a background to understanding the ethical dimensions of Telecare services in home care, it is necessary to explore the prevailing understandings of dementia by contrasting two models; the ‘old culture’ and the ‘new culture’ of dementia care (Kitwood 1997).

A predominantly ‘organic model’ (Cheston & Bender, 2003) has been understood to dominate the ‘old culture’ of dementia care. This ‘old culture’ has arisen from a predominantly neuro-physiological view of the various illnesses that contribute to dementia. Its associated institutional practices are primarily concerned with the alleviation of symptoms, meeting basic physical needs and safeguarding the ‘patient’. In the ‘old culture’ any cognitive deficits or problem behaviours are seen as symptomatic of an underlying illness, and not as universally human communicative attempts (Stokes & Goudie, 2002). Furthermore, a prevailing view of the person with dementia’s memory as inevitably deteriorating means that little attention can be paid to the everyday communicative contexts in which memories are presented as versions of an interactive self (Potter, 1996). Such views on dementia by the ‘old culture’ are highly ethically significant because in its care regimes, people can be ‘batched’ in terms of clinical, behavioural and ‘riskiness’ patterns. Therefore in such contexts, a sense of the continuing intrinsic dignity of the person risks being lost.

Yet, the solely bio-medical model of dementia has been challenged because there is no clear relationship between damage to specific parts of the brain and clinical features (Kitwood, 1997; Nuffield Foundation on Bioethics, 2008). For example, Kitwood (1997) contends that,

‘...at least some of the symptoms that are commonly found might be due more to a failure of understanding and care than to a structural failure of the brain.’

The resultant creation of ‘excess disability’ can result in further isolation of the person with dementia, rather poignantly imagined as follows:

'This is the subjective life of the person with dementia; a person who remains an active agent; an individual who makes decisions and initiates actions, while residing in a reality that resonates 'not knowing'; a person who as a consequence may be sorely misunderstood' (Stokes, 2000 cited in Anderson (2008: 83)).

How to alleviate the presumed oppression of people with dementia due to insensitive support has been a huge ethical challenge, only seriously addressed by the ‘new culture of dementia care’ (Kitwood & Bredin, 1992; Hunter, 1997). Its proponents argue that the bio-medical model has to
be synthesised with social and citizenship approaches, to achieve a more holistic view of the person with dementia in his/her social, cultural and spiritual milieu (Marshall & Tibbs, 2006). This means that,

*The stock plots of decline, rooted in the biomedical model of dementia and poor prognosis, are gradually being challenged by stories arising from psychosocial ... disability ... and citizenship ... models of dementia* (Baldwin 2005:1027).

‘New culture’ critiques of the standard ‘dementia script’ (Bryden, 2005) can also be understood to be allied to general concerns in the literature about the ‘pathologisation’ and over–medicalisation of disability generally. In parallel with the social disability movement, more attention is therefore given to the socio-environmental contours of the dementia experience. As a result, in the ‘new culture’, dementia is seen as arising from the dialectical interaction between neuropathology and the surrounding psycho-social environment. This can be expressed formulaically as,

\[ D = P + B + H + NI + SP \]

where:

P= Personality: ‘Resources for action’ - the sum total of a person psychological resources for maintaining well–being and dealing with sudden or progressive adversity;

B= Biography: The person’s life story including successes and losses;

H= Physical health which can interact for better or worse with any neurological impairiment;

NI = the actual damage to the brain such as the neurological lesions in Alzheimer’s disease/ Pick’s disease or the localised brain damage due to ‘mini-strokes’ in vascular dementia;

SP = Social Psychology is the human environment of the person with dementia, whether it enhances well being or undermines it (This can of course include the various domestic and assistive technologies that constitute this environment).

As a result, the emerging ‘new culture’ of care has major implications for ethically appropriate service design and delivery. A bio-medical perspective is of course retained because there is an essential role for professional judgement in differentially diagnosing dementias, following the stringent criteria laid down in DSM IV and ISN10, coupled with appropriately prescribed medication for any co-morbidity. As Stokes & Goudie (2002: xiv) argue:

*The medical model is not rejected, but we advance from pathology to person, and enter the realm of interpersonal relationships to ask the question: How well do I truly know what this person needs and how able am I to meet those needs*.
Advancing from 'pathology to person', leads to the ethical consideration of 'person centred care' which is pivotal to the 'new culture'. In relation to dementia, it should be noted there are different conceptualizations of 'person centred care' (Innes et al., 2006). Yet, attempts have been made at some kind of consensus:

'Person centred care has been defined as supporting the rights, values and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behaviour, even if it is difficult to interpret; maximising each person's potential and sharing decision-making' (Edvardsson et al., 2008 cited in Nuffield Council on Bioethics, 2008:15).

This accords with the emphasis on eudemonia or full human flourishing in neo-Aristotelian ethics (Bynum, 2006), in Rogerian humanistic counselling generally and in the natural law ethics of Aquinas. Yet, some versions of person centred care have been criticised as being too individualistic with inadequate attention given to the informal and formal relationships around dementia care. The work of Kitwood in particular has been criticised for not being methodologically rigorous enough, for using an excessively psycho-social model of dementia, for not paying adequate attention to the experiences of age-related embodiment, and for sometimes blaming carers for generating excess disability in their carees (Adams, 2008a). However, the concept of person centred care in dementia seems elastic enough to accommodate relational and systemic dimensions. For example, the NICE/SCIE Clinical Guideline 42 (National Institute of Clinical Excellence/Social Care Institute of Clinical Excellence, 2006) promotes positive relationships as an underpinning principle of ethical dementia care. Furthermore, this accords with the relational-systemic understandings of person centred care in the English National Service Framework for Older People (Department of Health, 2002). As a result, there is considerable overlap on some ethical fundamentals, as expressed in Brooker's 'VIPS' model of person centred care. Its 'Four elements' are:

- **Valuing people with dementia and those who care for them**
- **Treating people as individuals**
- **Looking at the world from the perspective of the person with dementia**
- **A positive social environment to enable the person with dementia to experience relative well-being** (cited in Innes et al., 2006).

In line with relationship centred approaches (Adams, 2008a), the latter 'element' can be expanded to include the structural, systemic and cultural impacts on the dementia experience. These 'Four elements' are of course inter-related, but for analytical clarity each will now be treated in turn.
3.1.1 Valuing people with dementia and those who care for them

Central to the notion of valuing people with dementia is the notion of ‘personhood’ as,

‘The standing or status that is bestowed on one human being by others, in the context of relationship and social being...’ (Kitwood, 1997:8).

Although it is recognised that there are different types of pathologies which constitute dementia, and that it is as much a social construction as a syndrome of brain illnesses, attention to ‘personhood’ creates a common ethical focus for ‘new culture’ perspectives. The goal of dementia care is therefore to nurture ‘personhood’ as far as possible where,

‘...people with dementia are presented as people with unique biographies, personalities and life circumstances, all of which interact with the neurological impairment. ... Fostering ‘personhood’ becomes central to dementia care’ (Downs, 1997: 598).

The appeal to respecting ‘personhood’ is also part of the canon of dementia self-advocacy:

‘How you relate to use has a big impact on the course of the disease. You can restore our personhood and give us a real sense of being needed and valued. There is a Zulu saying...” a person is a person through others”...Value us for what we can still do and be, and make sure we retain social networks’ (Bryden, 2005; 127).

The ‘fostering’ of personhood by formal and informal carers should involve an ethically vigilant rejection of ‘malignant social psychology’ (Kitwood, 1997; 2002). Elements of malignant social psychology include, stigmatising, labelling (e.g. as 'Wanderer'), unjust accusations and treachery (such as misinforming people about the 'benefits' of assistive technology). In contrast, the 'new culture' highlights ‘positive person work’ which means validating and affirming the individual in a safe physical and psychological space. It is now known that effective communication can take place even at advanced stages of dementia (Goldsmith, 1996), provided appropriate methods are used in the context of a validating relationship.

It is significant that Brooker’s VIPS model applies both to the person with dementia and the network of care relationships in which he/she is embedded. Yet, two salient observations have to be borne in mind by the DHC professional:

- Family or care relationships are not always harmonious. Sadly, dementia can too often be experienced in dysfunctional relational contexts. The DHC professional, when cast in a conflict resolution role, often has to deal with inevitable relational tensions when care options are being negotiated. For example, ethical dilemmas involving balancing the goals of protection and empowerment of vulnerable service users are frequently at the heart of professional practice with dementia. This means that in relation to any assistive
technological services, the unsettling ethical question of ‘Whose needs and interests are really being met?’, has to be honestly explored if genuine person centred care planning is to be achieved (Section 4.1.2, Chapter 4).

• The presumption of the need for care in many situations of dementia does not deny that ‘care’ is a highly contested concept, as discussed in the ‘social construction of disability’ literature. Sometimes terminologies of ‘support’ and ‘help’ may be the self-chosen constructions by service users (Shakespeare, 2000). The disability literature’s problematisation of ‘care’ may be as applicable to some people with mild to moderate dementia as anyone else. This is because such people may insist on self-support, rejecting any offer of informal input or home care services. It is therefore not surprising that the Dementia Epidemic recommends supporting forms of ‘self care’ for some people with dementia, to respect the full spectrum of self-empowerment (Alzheimer Scotland, 2007).

Yet, while acknowledging possible relational conflicts and contestations about ‘care’ for people with disability generally, the cognitive limitations of progressive stages of dementia warrant some kinds of sustained committed input from others. In any case, ‘Ethic of Care’ perspectives argue that all of us, whether impaired or not, have fluctuating life-course dependencies (Tronto, 1993). As a result, we are all to different degrees both givers and receivers of ‘care’. This has informed Tronto’s (1993), definition of ‘care’ as follows:

‘...a species activity that defines includes everything we do to continue, maintain, and repair our “world”, so that we can live in it as well as possible’ (Tronto cited in Brannelly, 2008: 248).

Barnes & Brannelly (2008) therefore argue that a rapprochement is possible between social disability and ‘Ethic of Care’ perspectives for complex dependency conditions like dementia. As the condition of dementia progresses, forms of informal and formal care will therefore be inevitable. The first element of Brooker’s framework also means valuing the people who provide such care as key partners in the caring experience as well as the service user him/herself (Section 3.2 & Section 3.3, this Chapter). This seems to accord with ‘relationship-centred’ perspectives in dementia care (Forbat, 2008).
3.1.2 Treating people as individuals

In the ‘old model’ it is common practice to aggregate people into groups, with common symptoms, so that a person becomes a ‘case’ and his/her individuality can be lost sight of. What the ‘new culture’ emphasizes is that people have unique personalities and biographies that can shape the dementia experience for them. As an ethical requirement, careful attention has therefore to be given to the personal life experiences of the individual with dementia. But this attention has to be forward-looking as well as past-reviewing, using a balanced approach for addressing personal strengths as well as weaknesses (Alzheimer’s Society, 2003). The DHC professional will appreciate that this personalized attention might involve the potential for rehabilitation (Marshall, 2006), sometimes using assistive technologies as ‘cognitive prosthetics’ (Stokes, 2002).

3.1.3 Looking at the world from the perspective of people with dementia...

There are major advances in ‘hearing the voice’ of the service user as evidenced in the practice literature generally. This also accords with 'Ethic of Care' perspectives such as Tronto’s (1993) model of care as involving 'attentiveness, responsibility, competence and responsiveness'. For example, the latter stage is highly empathetic 'allowing the carer to consider the other's position as that other experiences it' (op. cit, 136). Attention is therefore increasingly drawn to the views of people with dementia themselves on how others relate to them:

'We need to be given the same choice as you, even though we cannot tell you clearly what choice we want to make. And we should not be forced into a pattern of behaviour that simply suits ...your own ideas of what we should be doing. Think of us as an individual, not just a care-recipient' (Bryden, 2005: 128).

Sensitive service design is a clear ethical imperative and there are welcome developments in this field; notable examples including Moriarty & Webb (2000) on home care services, Proctor (2001) on listening to older women with dementia and Innes (2005) on rural home care services. But much more end-user participation remains to be achieved, especially in the assistive technology design field to promote ‘user centered design’ for dementia support (Robinson et al., 2007).

3.1.4 A positive social environment to enable the person with dementia to achieve well being

There is growing ethical sensitivity that the social environment can have significant effects on service users with dementia for better or for worse. This is in line with broader conceptualisations of some mental illnesses as occurring 'between' people rather than 'located in a person' (Forbat,
People with dementia can feel devalued in their interactions with significant others, leading to a ‘vicious spiral’ of lower mood and erosion of self esteem (Cheston & Bender, 2003). This is because they can internalise stereotypes of ageism and dementia, perhaps reinforced by other stereotypes of gender, sexual orientation and/or minority ethnic status. But Kitwood (1997) asserts there is still much scope for ‘positive person work’ to nurture the personhood of the person with dementia and promote quality relationships. As he points out, people with dementia can give to relationships and wider society as well as receive from them. Yet it is the ‘citizenship’ aspect of the ‘new culture’ that is perhaps the most underdeveloped (Marshall & Tibbs, 2006). As regards individual citizenship, there is much potential for creative expression through art work, music and drama. As regards collective citizenship, Cheston & Bender (2003) argue that the improvement in services for older people must involve some collective struggle to parallel successful advocacy for people with learning disabilities. But the history of collective campaigning for older people has been weak, compared to the disability movement or informal carers’ movements. Given the strong value base of social work in social justice, it would seem that social workers will have a key role to play in such movements. The DHC professional will note that in the future, access to assistive technological services may therefore be claimed as a 'right' by some people with dementia as part of a social justice agenda for technological and digital inclusion.

3.2 The Significance of Informal Care for Older People with Dementia

For the purpose of clarity, this Thesis refers to the person with dementia at home as the 'service user' or 'end user' and their carers will be referred to as informal or formal carers. Yet, the author is also mindful of the frequent dyadic and triadic nature of dementia care. Informal carers will often be service users in their own right and indeed may have some form of dementia themselves.

The significant role of informal care is increasingly recognised in the dementia care field. For older people in general, informal care remains the main self-reported source of support (Phillipson, 2002). It has been estimated that, ‘for Great Britain as a whole, approximately 80 per cent of people aged 65 and over living in private households, who have help with domestic tasks, rely exclusively on unpaid informal help’ (Pickard et al. 2000 cited in Pickard, 2004). In addition, there is evidence that where older people are cared for at home, most can name a main carer (Bauld et al., 2000). But if informal welfare is still seen as the linchpin of community care, its sustainability cannot be taken
for granted due to demographic and structural changes in society (Nolan et al., 1996; Ungerson, 2003).

Given the relational investments preceding much dementia care, and despite frequent ‘burden of care' discourse, caring for someone with dementia can be rewarding (Adams, 2008d). However, caring for someone with dementia does undeniably present cumulative challenges including,

'... nocturnal wandering, faecal incontinence, in inability to wash, dress or feed unaided, immobility and risky behaviour such as using a gas cooker' (Sanford, 1975 in Adams, 2008d: 90).

Such intensive caring can have profound effects on the psychological health of carers and it is believed that carers of people with dementia ‘experience greater strain, distress and higher levels of psychological morbidity than carers of other older people’ (Alzheimer’s Society, 2008:4). We must recognise that carers for people with dementia are often older people themselves since current estimates are that 68% of dementia carers are over 65 and 12% are over 80 (Nuffield Council on Bioethics, 2008). We must also consider the spill-over effects of carer stress on other household members (Adams, 2008e). In addition, informal carers for dementia have progressively to cope with relationship changes -the ‘living bereavement'- and frustratingly impaired communication with a loved one. As well as bearing considerable physical and emotional responsibilities, informal carers may also have legal responsibilities, playing significant roles as service ‘gatekeepers', advocates, welfare attorneys and legal guardians for the cognitively impaired person (Keywood, 2003).

Furthermore, informal carers can be significant adult service users in their own right and a welcome step has been their entitlement to separate carer assessment as under the Carers’ (Recognition and Services) Act (1995). But there is no statutory duty on service providers to provide additional help for an informal carer on the basis of his/her carer’s assessment. Despite progression in policy initiatives such as the English National Strategy for Carers (Department of Health, 1999), services providing direct or indirect support for carers are frequently criticised as under-resourced and insufficient (Pickard, 2004). An apparent carer-friendly policy rhetoric is also criticised by 'Ethic of Care' proponents who criticise its excessively 'instrumental' conceptualisation of care. Instead they advocate more official recognition of the multidimensional and reciprocal aspects of caring (Lyod, 2002; Henderson & Forbat, 2002; Sevenhuijsen, 2003). However in England, the recent proposal of a ‘New Deal’ for carers includes the promise of adequate respite, the development of ‘expert carer’ programmes and the funding of a helpline (Department of Health, 2007b). Similar initiatives have been announced in Scotland (Scottish Executive, 2006). It remains to be seen how successful these initiatives are and how they might incorporate assistive technological services/Telecare as part of
informal carers’ support.

3.2.1 The special case of co-resident carers

One key dimension of the caring experience may be whether the informal carer is co-resident or extra resident since,

'Sharing a household radically affects the experience of caring, and co-residence alerts us to the important ways in which caring is not just about the performance of tasks but the consequences of a relationship' (Twigg & Atkin, 1994: 9).

Co-residency can be a key factor in determining who takes on informal caring roles in the first place, part of the bedrock of normative views on family obligations (Finch & Mason, 1997). There also seem to be significant differences between the roles and caring patterns of co-resident versus resident carers in general. On a range of informal care inputs, co-resident carers, usually spouses or filial relatives, ‘are often those who provide the most intensive informal care inputs, and assist with the widest range of activities’ (Bauld et al., 2000: 234). In Scotland, the availability of free personal care for older people may be easing the burden of physical personal care somewhat.

A co-resident carer may also invest much emotional energy in keeping a person with dementia at home, in order to respect that person’s prior or ongoing preferences. Forms of ‘preservative care’ (Nolan et al., 1996) may be specially significant in the home care of people with dementia, because carers may want to preserve the personality of the person with dementia in the way they remember it, yielding pay-offs to the ongoing relationship (Hope & Oppenheimer, 1997). Accordingly, some qualitative studies on ‘coupledom’ in dementia have suggested that participants construct

‘...a ‘nurturative relational context’ in which the two main goals were to, (1) sustain the quality of the spouses’ relationship and (2) maintain the self-image and agency of the person with dementia’ (Adams, 2008e:108).

Care can often be reciprocal so that the person with dementia may him/herself be caring for a partner with other needs, as encapsulated in the following comment:

‘For many of the married couples, there was a strong element of reciprocity, as summed up by Mrs ... in the phrase: ‘I’m his leg and he’s my memory’ (McCreadie & Tinker, 2005:11).

Because of the joint interests and needs in such a relationship, the DHC professional will appreciate that a strong ethical case can sometimes be made for forms of ‘joint assessment' (Nuffield Council on Bioethics, 2008).
But DHC professionals will also be aware of the potential for disabling forms of care especially in dementia contexts (Adams, 2008a). For instance, Clarke (1999) laments the kinds of ‘de-skilling’ of people with dementia that can inadvertently be brought about by carers; sometimes because it seems quicker and safer for other household members to do everyday tasks like making a hot drink. More seriously, carers may also try to control the home caring situation to maximise safety but can over protect the user with dementia. This is particularly noticeable in research on home falls management, where carers of people with dementia use a variety of strategies to prevent falls and to minimise harm when a fall occurs (Buri & Dawson, 2000). Such controlling practices, even with benign intent, can be ethically suspect. Because views about care even in the most loving relationships will not always coincide, conflicting agendas can exist between service users and their carers (Parker & Clark, 2002), sometimes yielding ‘decisions’ by ‘proxy’ carers to collude with paternalistic practice (Heaton, 1999).

The DHC professional in designing a range of service interventions such as Telecare, therefore needs to very aware of such dynamics in dementia care relationships and of the legal basis for any carer decision-making as attorney or guardian. More detailed consideration will be given to this topic in Chapter 4 of this Thesis.

3.3 The Significance of Formal Care for Older People with Dementia.

The evidence suggests that ‘provision of domiciliary care can postpone or reduce permanent institutionalisation’ for older people in general (Arksey et al. 2002 cited in Pickard, 2004: 47). Research with people with dementia themselves also shows they want much greater choice in how their home care services are designed and delivered (Bamford & Bruce, 2000). In addition to help with activities of daily living, it is noted that people with dementia can derive relational as well as functional benefits from well-tailored home care services (Cobban, 2004). The targeting of domiciliary care services for more dependent client groups such as those with dementia is therefore to be welcomed. However, the following barriers to effective home care implementation are particularly noteworthy for the DHC professional:

- In Scotland, the Dementia Epidemic (Alzheimer Scotland, 2007) and Meeting Our Needs (Alzheimer Scotland, 2008) draw attention to service deficits for people with dementia and their carers, as currently perceived. There seems much scope for further expansion of conventional home care services, since at present only around 11% of people with dementia
at home receive home care, way below the working target of 28% set out in official Scottish policy.

- In relation to the quality of existing services, Cobban (2004) notes that despite improvements in the culture of dementia home care, home care workers continue to be ‘under-trained, under-valued and under-managed’ (op. cit: 61). This observation is reinforced by a report on the state of dementia care in England, where perceived skills deficits in the domiciliary care workforce were identified by Community Psychiatric Nurses (National Audit Office, 2007).

- There is ongoing concern that targeting may be accompanied by allocation biases against people with assumed informal carers (Bauld et al., 2000), despite much rhetoric about ‘carer-blind practice’ in care management (Arber et al., 1988). In relation to intensive domiciliary care, Curtice et al. (2002) found that much ‘user’ and carer dissatisfaction arises from poor care management. In some instances for example,

  ‘Informal carers ... found a large part of their supervisory and monitoring role to be taken up by monitoring replacement carers, while older people themselves had to train people on the job who had no awareness of their needs’ (op. cit: 79).

This criticism is reinforced by more recent observations that home care services in Scotland suffer from a postcode lottery, are often too brief, too 'task orientated' and not 'support orientated' enough (Alzheimer Scotland, 2008).

- Unsatisfactory home care services mean that informal carers might not just have to compensate for inadequate instrumental care, but also carry out ‘sentimental work’ to compensate for the deleterious impact of some forms of formal care. This kind of compensatory emotional nurturance may be particularly significant for carers of people with dementia, generating further carer stress and service dissatisfaction.

3.4 Between Two Cultures of Dementia Care?

The DHC professional may agree that though ‘new culture’ conceptualizations are widely accepted, in practice we still seem to stand between old and new cultures. Cheston & Bender (2003) are pessimistic we can ever fully transform the culture of dementia care because of high costs in terms
of money and human resources. However, we may be edging towards a 'new paradigm' (Hunter, 1997) gradually. This is because there have been several positive developments in the field of dementia care in the last 15 years or so, as discussed by Goudie (2002). Her observations are listed as follows and this author has added additional pertinent comments. These include:

- Awareness-raising of dementia through frequent media attention, the publishing of autobiographies and the growth of support groups, including online support groups;

- More positive awareness of ageing generally and more visible role models;

- New drugs offering symptomatic alleviation such as Aricept in the case of Alzheimer’s disease;

- The development of Memory Services and earlier diagnosis, leading to better lifestyle planning and granting of powers of attorney. However, the UK still lags behind other European countries in its early detection figures for dementia (National Audit Office, 2007). Similarly, the growth in the role of local specialist dementia advisors is noteworthy (Cobban, 2004);

- Associated growth in better Care Management, partnership working and Single Shared Assessment tools such as CARENAP D and ‘Building on Strengths’ (Alzheimer’s Society, 2003). Such practices produce a much more rounded view of the person with dementia since strengths are highlighted as well as deficits, needs and risks. CARENAP also highlights ‘unmet need’ in a local population, useful for service planning purposes (Meaney et al., 2005);

- Working with people with dementia is now seen in a more positive light across a range of disciplines and is less of a Cinderella profession (Marshall & Tibbs, 2006);

- Growth in the UK’s Dementia Service Development Centres for research and consultancy, such as those in Stirling and Bradford;

- Growths in self advocacy by people with dementia themselves. There is now more
Managerial representation by people with dementia themselves in support organisations and at conferences of the Alzheimer’s Society (Cantley & Bowes, 2004), reducing the previous over-representation of dementia service users by carers;

• There is an appreciation of the potential for growth, self-development and rehabilitation in early stage dementia (Marshall, 2006; Nuffield Council on Bioethics, 2008), despite the inevitability of a progressive deterioration in most dementias;

• Growth in informal Carers’ advocacy and campaigning, though it is recognized that the interests of services users and their carers do not always coincide;

• UK Law reform such as the Adults with Incapacity Act (2000) in Scotland arising from more enlightened views on mental capacity, has generated a robust legal framework for supported and proxy decision making.

However in her discussion, Goudie (2002) also notes several barriers to improvements in better service delivery for people with dementia, to which this author has added recent relevant observations from the literature:

• A persistent culture of ageism and the structural disadvantage of older people relative to other sub-groups in the population. Furthermore, the persistence of stigmas relating to ageing and dementia and their internalisation, can be obstacles to seeking diagnosis, treatment and support (Nuffield Council on Bioethics, 2008);

• The persistence of stigma related to unsatisfactory media discourse about dementia with continued over use of disease-laden terminology. Carers can be co-opted to such discourse resulting in the re-assertion of the solely biomedical model which aggravates public anxieties about Alzheimer’s disease in particular. Even fund raising campaigns can also have a bias to this kind of language and imagery (Cheston & Bender, 2003);

• The persistence of ‘old culture’ practices such as the continued dominance of ‘expert’ professionals in planning services and less attention given to the real experts i.e. service
users themselves and their carers. This is because people with dementia can sometimes be seen as low priority in a typical GP's case-load, perhaps only amounting to about 20 cases in a case-load of 1500 to 2000 people. Rather worryingly, some of the recent National Audit Office (2007) report suggests the re-entrenchment of 'old culture' attitudes to dementia by some GPs. Primary Care practices may therefore need to be more incentivised to provide earlier screening for dementia and its more holistic treatment;

- The relative disadvantage of people in minority ethnic groups (and perhaps sexual minorities) when it comes to dementia services;

- Demographic changes which make the future reliability of both formal and informal care uncertain.

It is therefore not surprising that some suggestions for improvements of services and social attitudes have been proposed by people with dementia themselves and their carers, in recent Focus Group research (National Audit Office, 2007: 58-59). The study recommendations include:

- Need for more public awareness-building and education;

- Promotion of timely diagnosis including appropriate training for GPs;

- Production of information pamphlet on day of diagnosis;

- A single point of contact for information on dementia.

- Overall, a more strategic approach to dementia management in the UK. Thankfully, there are moves in this direction as in the proposal of a ‘Dementia Strategy’ for England in late 2008 (Department of Health, 2007a).

3.5 The Value of Home for People with Dementia

Central to the promotion of a dementia-friendly culture is the value of home as a locus for the well-being of an increasing number of people with dementia. In general, older peoples’ preferences to ‘stay put’ at home for as long as possible with appropriate levels of care are consistently corroborated by research (Heywood et al., 2002; Audit Commission, 2004b). The most obvious benefits seem to be the control of one’s own environment and role maintenance, the retention of better cognitive function, and expectations of better ongoing health. Given the fundamental
requirement for the nurturance of ‘personhood’ in dementia (Kitwood, 1997), home may be the main nexus of highly valued kin and social relationships. Indeed for many people with dementia, the sustainability of home life is crucially dependent on the co-residency or regular support of informal carers and significant others.

Although estimates vary, it is currently estimated that between 36 percent and 53 percent of people with mild to moderate dementia in the UK live at home (Alzheimer’s Society, 2007). People with dementia seem to be no different from older people in general in their preferences to ‘stay put’ but adequate and appropriate home care services have to be in place to support this preference. There is strong evidence for the value of intensive domiciliary care packages in sustaining the home care of people with dementia as demonstrated in the PSSRU models (Challis et al., 1997; Moriarty & Webb, 2000; Means et al., 2003), provided these services are delivered ‘sensitively and flexibly’ (Audit Commission, 2002b). Likewise, the National Service Framework for Older People (Department of Health, 2002) (England & Wales) highlights the need for ‘comprehensive, multidisciplinary, accessible, responsive, individualised, accountable and systematic’ services across care settings’ (Crawford & Walker, 2006).

The self-perceived benefits of ‘staying put’ may also be linked to its putative advantage over institutional models of care. It is noteworthy that dementia is the most significant risk factor in the likelihood of nursing home placement for older people, increasing it by 47% (Siotia & Simpson, 2008). The DHC professional will be mindful that the value of home for people with dementia is often constructed by contrasting it with the perceived disadvantages of permanent or temporary institutional care, outlined as follows:

- Although care homes now seem much more humane as a result of legislation and ‘new culture’ influences, criticisms of such ‘controlled communities’ and their ‘warehousing’ practices still abound in the literature (Adams, 2008i). For example, McColgan (2004) is very critical of ‘old culture’ practices in her study of ‘Deer Grange’ Nursing Home. She observed that a ‘Cult of time and task’ predominated with an over emphasis on ‘bed and body work’ and the ‘infantilisation’ of residents. Constant surveillance of residents because of minimal staffing can lead to the creation of ‘excess disability’. Such criticisms are also shared by Adams (2008j) in his condemnation of some forms of dementia nursing care as abusive:

‘I hear troubling stories about people with dementia not being fed, not receiving drinks,'
getting bruises... I wonder whether some people suffer more from the effects of bad nursing care than from dementia itself! (op. cit., 279).

- There is also strong evidence that hospital care can disorientate and destabilize people with dementia and may cause irreversible harm, possibly precipitating admission to a care home (National Audit Office, 2007). In addition, iatrogenic risk to patients in hospitals ranges from preventable medical errors (Fieschi, 2002) to hospital-acquired infections. Such welfare concerns are compounded by general concerns about dementia-specific skill deficits in hospital staff.

Ethically, the Community Care momentum for directly supporting intensive home care for people with dementia and indirectly supporting their informal carers therefore seems welcome. Assistive Technological service additions to this support mix may therefore enhance the sustainability of home care for people with dementia. It is also recognised that we are witnessing a growing spectrum of semi-institutional dementia-support models, often supported by technology. For instance, independent households can be embedded in Sheltered Housing and ‘Housing with Care’ complexes, the latter being increasingly endorsed for supporting people with dementia (Croucher et al., 2006; Vallely et al., 2006).

However, the DHC professional needs to bear the following caveats about ‘romanticising’ the home in mind:

- Under the mask of privacy, homes can be sites for the oppression and exploitation of caregivers, with a disproportionate burden of care still born by women. ‘Our rosy picture of home is thus often parasitic on widespread but socially unjust roles for women caretakers’ (Noddings, 1995).

- Living ‘at home’ with family can be as oppressive as conventional institutional care. Bryden (2004) warns that ‘malignant social psychologies’ can persist from previous household histories since,

  ‘... the home is often where past conflicts, present tensions and well worn patterns of behaviour may profoundly affect the expression of dementia’ (op. cit., 3);

More seriously, the apparent opacity of homes may mask the mistreatment and even abuse
of older users or their informal carers.

- Homes may be workplaces for increasing numbers of people providing forms of domiciliary care but they are not always safe spaces for paid carers and professionals. As Taylor & Donnelly (2006:252) point out,

  'Home care is not a panacea for the high costs of institutional care. There are significant hazards facing home care workers in the homes of clients including health hazards, injuries in moving and handling, verbal abuse and aggression.'

People with dementia like other vulnerable adult service users are by no means immune from the latter observation and carers may be at risk from physical as well as verbal aggression. Accordingly, under the Health and Safety at Work Act (1974), there are legal requirements on service providers relating to the workplace. As Employees, home care workers also have a duty 'to take reasonable care of themselves and others who may be affected by their acts or omissions at work' but this is becoming increasingly challenging in practice (Taylor & Donnelly, 2006). Increasing intensive home care packages and 'hospital at home' technologies may compound this challenge in the future.

The DHC professional has to be aware of these significant ethical dimensions of staying at home before considering any service interventions. But the home, for better or worse, remains the site of autonomy and vital relationships for a growing sub-population of older people with dementia. Home is thus the locus of the new Telecare services and the ethical dimensions of this innovation become the subject of Chapter 4.
DEVELOPING AN ANALYTICAL FRAMEWORK FOR THE ETHICS OF TELECARE IN THE HOME CARE OF PEOPLE WITH DEMENTIA

This Chapter aims to critically examine the ethical issues at the intersection of Telecare services, home care and dementia, as currently conceptualized in the literature. It is primarily aimed at Dementia Home Care (DHC) Professionals.

A conceptual map of the main ethical issues for this Chapter is now tabulated as follows:
### Figure 9: Thematic outline of Chapter 4

<table>
<thead>
<tr>
<th>Topic</th>
<th>Ethical Opportunities</th>
<th>Ethical Challenges</th>
<th>PRACTICE EXAMPLES</th>
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<tr>
<td><strong>QUESTION 1:</strong> To what extent are Telecare services facilitating the harmonisation of ‘Person Centred Care’ with ‘User Centred Design’ in dementia home care?</td>
<td>The principles of ‘User Centered Design’ and ‘Person Centered Care’ seem to harmonize. Yet, holistic assessment may mean that any assistive technological services may be inappropriate. If technological services are considered, ethical application of ‘User Centred Design’ is required. To this end, good practice models from the (electronic) assistive technology literature exist.</td>
<td>The DHC professional will note general challenges to implementing ‘Person-Centred Care’, from the dementia literature. Before commissioning any Telecare, the DHC professional has to ensure valid consent to any proposed interventions. If valid consent is not possible due to insufficient capacity, the DHC professional has to facilitate supported decision-making? Although our knowledge base of Telecare services for dementia is very limited, the research material available to date is used to explore the following Questions 2-4 of this Thesis.</td>
<td>EXAMPLE 1: ENABLE EXAMPLE 2: ‘AT HOME WITH AT’ EXAMPLE 3: ‘SAFE AT HOME’</td>
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<tr>
<td><strong>QUESTION 2:</strong> Question 2: To what extent are Telecare services offering enablement or containment for people with dementia at home?</td>
<td>The DHC professional will appreciate that Telecare services may enable the maintenance of Home as site of empowerment. ‘Lifestyle monitoring’ enables home safety, security and risk reduction. Telecare data may allow the early detection of mistreatment or abuse. Lifestyle monitoring studies suggest people with dementia self-manage more than previously thought. Thus, there may be valuable rehabilitative potential from Telecare services.</td>
<td>The DHC professional has to be sensitive to varying constructions of risk by professionals and service users. Individually, Assistive and Telecare Technologies inflect patterns of home care risk and may introduce new forms of risk. Collectively, the ‘electronic gaze’ of Telecare can stratify and contain people with dementia solely in terms of risk analysis.</td>
<td>EXAMPLE 4: ETHICAL ISSUES AROUND TELECARE AND ‘WANDERING’.</td>
</tr>
<tr>
<td>Question 3</td>
<td>Ethical Opportunities</td>
<td>Ethical Challenges</td>
<td>Practice Examples</td>
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<td>How are Telecare services impacting on the interpersonal relationships between the person with dementia and significant others, particularly informal and formal 'carers'?</td>
<td>Telecare services can re-deploy carers more productively. 'Lifestyle monitoring tools can be very useful for care planning. Telecare may contribute data for 'Carers Assessments'. Supportive Technology may ease burden on informal carers.</td>
<td>Telecare services can be a cheap substitute for human care. The DHC professional has to be vigilant about particular risks of 'disembodied' care to people with dementia. If carers are co-resident, home technologies can be problematic.</td>
<td><strong>Example 5:</strong> Smart Homes for People with Dementia.</td>
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<tr>
<th>Question 4</th>
<th>Ethical Opportunities</th>
<th>Ethical Challenges</th>
<th>Practice Examples</th>
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</thead>
<tbody>
<tr>
<td>Question 4: What are the ethical implications of the formal service re-configurations that Telecare is introducing?</td>
<td>Telecare can advance service partnerships through 'Single Shared Assessment' and care planning. Telecare data can help to monitor home care service quality.</td>
<td>To implement Telecare, partnership working may be problematic. Telecare needs to be coupled to (informal and formal) rapid response mechanisms. Telecare 'response protocols' require careful negotiation and regular review. Telecare creates new challenges for data governance. Telecare services cannot compensate for deficiencies elsewhere in the formal care system.</td>
<td><strong>Example 6:</strong> Current Ethical Challenges Suggested by Telecare Implementation in England. <strong>Example 7:</strong> Author's Own Practice: Are Telecare Services Really Appropriate for Some Forms of Dementia?</td>
</tr>
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</table>

### 4.1 QUESTION 1: TO WHAT EXTENT ARE TELECARE SERVICES FACILITATING THE HARMONISATION OF ‘PERSON CENTRED CARE’ WITH ‘USER CENTRED DESIGN’ IN DEMENTIA HOME CARE?

 Appropriately designed Assistive Technology is generally seen as beneficial for people with dementia by advocates of the ‘new culture’ of dementia care, subject to thorough holistic assessment of end users with dementia and any carers (Marshall, 2000; Woolham, 2006b). Ethically acceptable Assistive Technology design therefore has to harmonise with the ‘dementia friendly design’ of home care services more generally (Marshall & Tibbs, 2006). In order to inform DHC professional reflection, this Section 4.1 addresses ethical issues on how the fundamental option for ‘person centred care’ can blend with ‘user centred design’ for Telecare implementation. In order to address these issues, it uses some of the rich empirical material already available from stand-alone technologies for people with dementia. It also attempts to make conceptual links with some of the literature on the ethics of healthcare technologies in general. This Section then culminates in practice examples which illustrate some of the ethical issues raised. A Thematic outline of ethical
issues relevant to Question 1 is provided as follows:

### Figure 10: Thematic Outline of Question 1.

<table>
<thead>
<tr>
<th>Section</th>
<th>Study Question</th>
<th>Main Ethical Issues addressed in this study</th>
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<tr>
<td>4.1.</td>
<td>To what extent are Telecare services facilitating the harmonisation of ‘Person Centred Care’ with ‘User Centred Design’ in dementia home care?</td>
<td>A presentation of the fundamentals of holistic person centred assessment for dementia home care is outlined. This may mean that we do not need any technology for person centre care in the first place as other forms of service may be more ethically desirable. If assistive technology is used, the DHC professional has to ensure valid consent to any intervention, but dementia presents challenges to securing valid consent. Negotiating care packages with carers and others presents legal and ethical challenges in any case. The DHC professional also needs ethical vigilance about other stakeholder interests such as those of suppliers, professionals and carers. If Assistive Technology is used, the ideals of ‘User Centered Design’ and ‘Person Centered Care’ seem to harmonize. Ethical design of Telecare services can draw on a rich vein of lessons in the general assistive technology (AT) literature for dementia care. Yet, a knowledge gap exists about the ethical impact of Telecare services for which the existing AT base is insufficient. However, speculative material does exist in the literature as an aid to illuminating the further Questions of this study.</td>
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#### 4.1.1 Do we need any assistive technology or Telecare in the first place in dementia home care?

The Alzheimer's Society (2006) insists that a thorough person-centred assessment should always precede the use of any technology in a care package. For the DHC professional, this means that a much stronger ethical case may have to be made for better home care services or more structured support for the person’s informal carers(s), even though these inputs may be more resource intensive. Beech & Roberts (2008) also remind us that a service user’s right to refuse any assistive technological package is fundamental, even if clear potential benefits have been anticipated. In developing an ‘ethical protocol’ for the ASTRID project, Marshall (2000) therefore continually urges the question ‘What are the alternatives to technology?’ Similarly in relation to designing Telecare services, Brownsell & Bradley (2003:74) propose that a more ‘fundamental ethical question’ ought to be:

‘Should this type of [Telecare] monitoring be provided...should society be looking to provide more ‘hands on care’, should care be provided in peoples’ homes or in the form of residential care’?

This comment is in line with much of the literature advocating the supporting of older peoples’
domestic needs with 'no-tech' or 'low-tech' solutions. Accordingly, Heywood et al. (2002) note that,

'...if older people themselves were being asked what kind of assistive technology they might like ...would they not perhaps ask for the means to clean windows and change light bulbs and curtains, do the housework or gardening...'.

For people with dementia, the recent report 'Dementia UK' reinforces such observations by recommending the value of 'low level support':

'People with dementia need improved home care support packages, including low-level support to retain their independence and dignity. The number and extent of home care packages must be increased. In addition it is time to bring back home help services such as help with cleaning, shopping, DIY and gardening' (Alzheimer's Society, 2007: xx).

The upshot of such observations means that, 'sometimes better practice might be to seek a different, non-technological solution to a problem' (Woolham, 2006b, 9). For example, Calder (2006) in her study of the 'South Lanarkshire Dementia Technology Initiative' reports that a curtain drawn across a front door at night prevented 'wandering' and worked for considerable time before considering more sophisticated solutions.

Orpwood et al.'s (2007) development of INDEPENDENT a music system designed for people with dementia seems a good practice example of a using a technology-free methodology. In seeking users' views, the researchers bracketed off any consideration of technology when listening to the views of music loving users. It was only after generating a 'wish list' of 'enabling aspects' and 'challenging aspects' of musical activities by the subjects with dementia, that matching technological prototypes were then proposed.

In designing a home care package, even where some kind of assistive technological service does seem appropriate, the DHC professional will appreciate that devices need not be overly sophisticated or involve any Telecare. Instead, stand alone devices may be deemed more appropriate. For example, the solution to an overflowing bath may be a simple 'magi plug' and not a Telecare-enabled flood detector. The choice of whether or not to incorporate any assistive technological services is therefore subject to the fundamental ethical baseline of holistic assessment for dementia-friendly service design.
4.1.2 The ethical contours of dementia-friendly home care services

4.1.2.1 The fundamental necessity for Holistic assessment in dementia home care.

Telecare services have to be commissioned in the context of holistic care planning, as the above figure illustrates. This shows that the entry point to any home care package is through the Single Shared Assessment Process (SAP). This means that the person carrying out an assessment for home care - such as the DHC Professional often in partnership with other professionals, has to pay careful attention to the ‘life worlds’ of potential service users, any co-residents and carers. As often happens in practice, the DHC professional may be encountering a potential user at a very vulnerable time in his/her life – such as undergoing a crisis or transition which might have triggered the referral in the first place. Such change may be particularly acute for someone with dementia.

Thorough assessment requires a working familiarity with best practice care-planning tools for dementia. These include the Assessment of Motor and Process Skills Test (AMPS) (Dunk & Doughty, 2006), the Alzheimer’s Society’s (2003) Building on Strengths and the Care Needs
Assessment Pack for Dementia (CARENAP D) (Meaney et al., 2005). Such tools encompass a 'bio-psycho-social' (World Health Organisation, 2002) understanding of dementia and attempt to address the 5 vital needs of the person with dementia conceptualised by Kitwood (1997) as ‘inclusion, attachment, comfort, identity and occupation’. According to Woolham & Frisby (2002), best practice with dementia therefore needs to highlight capacity and strengths as well as focusing on needs and risks.

The DHC professional will also be aware that people with dementia, whether or not they know their diagnosis, can under-report their needs (Meaney et al., 2005), unless careful exploration takes place. This may be due to a number of reasons such as memory problems, lack of insight, denial, or various kinds of learnt helplessness in coping with home-based challenges (Proctor, 2001). Because of possible power asymmetries, DHC professionals have to be very circumspect in how they present the risks and benefits of any service package. This is because drawing attention to skill deficits and risks may be very undermining for the potential service user and expose them to imagined criticism and rejection. This reality demands close attention to how carer and professionals define ‘need’, as evidenced in the CARENAP D methodology where the status of need as ‘met’ or ‘unmet’ is required from a ‘consensus’ of service user, care and needs assessor. As well as including carers and other stakeholders in a comprehensive assessment alongside the service user, a separate conversation might also be deemed necessary with them. This is not to deliberately exclude the person with dementia but recognition that carers may have concerns they feel unable to express in the presence of their caree. However, the DHC professional must be mindful that carers and users may have different perspectives and agendas (Parker & Clarke, 2002), necessitating careful negotiation about any home care package. For instance, it is noteworthy that individuals very in their receptivity to even apparently benign inputs so that,

‘One person’s relaxing and calming hand massage may be another person’s invasion of personal space and confinement’ (Douglas et al., 2004:179).

So the fact that a carer thinks something ‘will do you good’, does not mean the person with dementia will view any proposed intervention in this way.

As well as the content of any information, careful attention must also be paid to how the user is communicated with. Although ‘truth telling’ seems ethically fundamental, for some sensitive cases carers and professionals may decide not to disclose a diagnosis to the person with dementia as this may be seen on balance to be counter-productive. When dealing with the service user, it may not be appropriate to talk about ‘dementia’ at all as he/she may be unaware of any diagnosis. Instead interactive language should be used that is congruent with his/her own self-definitions of condition.
and lifestyle.

It can take considerable time for the necessary rapport and trust to build between DHC professionals, staff and people with dementia, yet managerial and resource pressures can often militate against this. With dementia, the DHC professional may be dealing with people who are non-self referrals and who might vehemently challenge any home care service proposals in the first place. Indeed the DHC professional may be seen as a threat to independence and a possible harbinger of institutional care.

Even when there is ease and trust in a relationship, people with dementia themselves frequently draw attention to the problem of others ‘outpacing’ them, part of the ‘malignant social psychology’ criticised by Kirkwood (1997). As Bryden (2005:139) pleads:

‘Just because we can’t express ourselves very well does not mean we have nothing to say. As our thoughts and words are tangled and confused, you will need good listening skills, being attentive to non-verbal cues... give us time to speak, wait for us to find the word we want to use and don’t let us feel embarrassed if we lose the thread of what we say.’

According to Friedell (2006), a dementia self-advocate, it is not so much information processing ability that deteriorates per se as the processing speed required for ‘normal’ conversations with those on the outside of the dementia experience. Indeed, Bryden (2005) claims that interaction problems arise more from ‘communication impairment’ than any ‘cognitive impairment’. As a result, the DHC Professional who is designing a home support package needs to pay careful attention to word-finding difficulties or slowed processes of speech, as well as limited concentration spans and possible sensory impairments. In order not to ‘outpace’ the user, information may have to be conveyed slower and in shorter phrases than 'normal' conversation, without patronising the listener. Allowance may also have to be made for repeat questioning and reassurance which may be emotionally challenging. The DHC professional will be already familiar with well researched practice recommendations such as in Adam’s (2008g) excellent chapter on ‘enabling dementia communication’.

A careful reflexivity on matching communication styles and a commitment to balancing varying perspectives is therefore a fundamental moral requirement of the DHC professional when carrying out any assessment for care planning. Whatever kinds of services are proposed, valid consent must be sought as discussed in the next sub-section.
4.1.2.2 Seeking valid consent for services.

In relation to services for dementia care generally, there are now an increasing range of practice examples where close attention is given to ‘hearing the voice’ of service users with dementia on services receipt (Moriarty & Webb, 2000; Innes et al., 2005). In relation to any service intervention, the ethical ideal of ‘valid consent’ therefore has to be sought. According to Hughes & Baldwin (2006), valid consent has to be,

- Fully Informed,
- Uncoerced,
- Continuing
- Competent

The first requirement of ‘fully informed’ consent draws attention to the content and form of communication. According to the Telecare Services Association ‘Code of Practice’ (Telecare Services Association, 2006), ‘the known risk and benefits of any kind of service have to be explained to the user’. From this standpoint, it must also be pointed out that there may be unknown benefits and risks. The DHC Professional is not a salesperson so must not over sell the technology and make claims that are not warranted. He/she must be very clear about what any technological package ‘can’t do’ as well as what it ‘can do’ (Calder, 2006). He/she has to disabuse the user and any carers of any excessive expectations of the technology itself or the Telecare service, mindful of the dangers of excessive dependence on over automation. The following caveat is therefore highly pertinent:

‘Avoid language that implies that the technology [sic] does more than it actually does... when in reality it does not’ (Mahoney et al., 2007: 224).

Because decision making can be difficult without experiencing an actual home-based Telecare service, the package selected by the potential user could initially be offered on a trial basis (Cash, 2006). For example, for the Hanover Telecare service, the minimum contract is 3 months so that the user is not over-committed to a package if Telecare is found to be unsuitable.

Similar to medical information giving, it must also be born in mind that insufficient or inaccurate information provision could lead to negligence litigation where ‘... the patient[sic] alleges that consent would not have been given had the implications of the treatment [sic] or the risks attendant thereon be properly understood’ (Hodge, 2008: 263). As yet, no case law is available to comment any further on this possibility for Telecare services, though such cases may well arise in the future.
Best practice in information giving is highlighted by the *Aztec Project* for people with dementia (Dunk & Doughty, 2006). In the Aztec Project, all involved in supporting the services user must have an understanding of the limitations of the technologies as well as its anticipated benefits. To this end, types of information in the Aztec Project include:

- A current information pack;
- A video/DVD showing the technologies in use;
- A demonstrator house;
- Demonstrations of portable equipment in the home of the potential user(s);
- Training courses and other resources for professionals and carers.

Using such a range and diversity of information sources and outlets, the capacity for full informed consent is therefore maximised (McCreadie et al., 2006). However, the other extreme of an overly ‘consumerist’ approach must also be avoided (Hughes & Baldwin, 2006) where users are given too much information on Telecare with too few pointers to its practical usability for themselves. This is clearly unproductive for people with dementia who can have short attention spans and are highly sensitive to information overload.

The second requirement that consent must be uncoerced is a clear ethical imperative. There must obviously be ‘zero tolerance’ for any form of overt coercion such as psychological threats, e.g. ‘If you don’t accept this Telecare service, you will have a serious home accident’. But there are subtle forms of coercion that need to be watched, themselves part of the ‘malignant social psychology’ criticised in Kitwood (1997). For example, there may be situations where an informal carer or neighbour stands more to benefit and a service user may be cajoled into accepting a Telecare package.

The third requirement relates to continuity of consent. The fact that someone agrees to do something once, does not remove the right to subsequently change his/her mind. This has implications for service review and withdrawal. With a service like Telecare, ongoing data logs can illuminate the review process, resulting in more finely tuned packages and better overall care planning. This is highlighted in Calder’s (2006:31) report on a 'Dementia and Assistive Technology Project' where ‘... the project was able to identify where participant needs were changing and amend care packages accordingly.’
The **fourth** requirement relates to competence (more used in medical contexts) or capacity (more used in legal contexts) to make decisions for one self.

It is possible to conceive of a spectrum of decision-making from autonomous decision making, via co-decision making to surrogate or proxy decision making. The ethical ideal is to promote autonomous decision making as far as possible though it must be realised that any service user may prefer co-decision making for any home support package. At the other end of the spectrum, any grounds for proxy decision making by a carer or advocate must have legal warrant under current UK legislation.

Although the possibility of impaired capacity must be seriously considered in any dementia case, having dementia does not mean automatic incapacity. This is because ‘competence’ is ‘graded’ and not ‘binary’ (Hope & Oppenheimer, 1997). This is expressed in the fundamental shift in UK legislation, from considering incapacity as having an ‘all or nothing’ status to viewing it as situation-specific. This legislation is a necessary corrective to paternalism where ‘experts’ and carers make decisions on behalf of people. In line with the legislation in Scotland and in England, for any proposed intervention, the capacity to give ongoing valid consent must therefore be presumed unless it can be demonstrated otherwise from an assessment of capacity by a GP or legally approved professional.

But forms of cognitive impairment such as dementia present ethical challenges. This is because the capacity to give consent can fluctuate. In the case of most dementias, as the person is cognitively deteriorating it seems unlikely that he/she will suddenly pass from having full capacity to having no capacity (Hope & Oppenheimer, 1997). While seeking autonomous decision making as an ethical goal, we can imagine we have enabled ‘autonomy’ of the cognitively impaired person in any decision making, when all we have achieved is some kind of ‘pseudo-autonomy’ (Jacques, 1997). The DHC professional therefore needs to pay attention to autonomy as an ongoing process, to determine if it is really genuine. For example, a person may later chose to reject any services such as Telecare despite initial acceptance. Obtaining informed consent has to be inclusive of adequate and sufficient information, yet it is hard to anticipate what the impact of an intervention such as Telecare might be on a particular end user. New effects might come to light, leading to rejection by the end user, even if this seems an ‘unwise decision’ to carers and others. Yet, ‘unwise decisions’ have to be respected and upheld under the Scottish legislation. But, in the interests of truth telling, the potential user has also to be advised of the consequences of what might seem an 'unwise
decision' (North Lanarkshire Council, 2007). For example, the DHC professional will appreciate that if a potential service user turns down any recommended inputs, he/she may be at serious risk if he/she remains at home without some form of supervision from Telecare services or formal care. This information has to be imparted not to put subtle pressure on the service user, but to alert him/her and any carers to the possible consequences of his/her choice (Hughes & Baldwin, 2006).

Where valid consent can be given by the service user with dementia, this is of course the ethical ideal, even if he/she has to consult significant others. But we also have to attend to the relational and household context of any decision making for assistive technological services. This is because choices about any domestic technologies or services may have been generally experienced as household choices and not individual ones (Antonides & Van Raajj, 1998). In any case, a lot of individuals will want to co-decide about any service intervention whether they have dementia or not. Accordingly, Gordon (2000) points out that few adult decisions in practice are ever made independently so that the preference for shared decision-making _per se_ should never be seen as indicative of mental incapacity. This observation accords with ‘Ethic of Care’ perspectives which highlight the reality of interdependency in care relationships (Tronto, 1993). So as a matter of principle, where a service user chooses to co-decide on a Telecare service, this should be supported. This may be because of a spousal or filial relationship where cooperative decision making has been part of the relationship history. However, there may be gendered or cultural components in decision making which may seem ethically dubious, such as a wife deferring to her husband. This observation may be particularly relevant for minority ethnic service users (Mahoney _et al._, 2007) or some religious believers. The DHC Professional may have to accept such deferral as a given, even if this is not congruent with his/her own value base. Where the individual wants to co-decide or cannot decide on his/her own, the ethical ideal would therefore seem to be ‘assisted’ or ‘supported decision making’ which is defined as,

> ‘. the process whereby a vulnerable person is enabled to make and communicate decisions with respect to personal care or his or her property and in which advice, support or assistance is provided to the vulnerable person by members of his or her support network’ (Gordon, 2000:68).

Although not as explicitly defined in UK as in Canadian legislation, supported decision making is implied in some of the terms of the English capacity legislation. For example, Principle 2 states,

> ‘The person must be given ‘all practicable help before anyone treats them as not being able to make their own decisions’ (Department of Community Affairs, 2007).

Where supported decision making is not possible, proxy service decisions (supported under
available legal channels such as Enduring Powers of Attorney and Guardianship Orders) must be made in the ‘best interests’ of the service user and involve the ‘least restrictive’ option. This will involve consulting the current wishes of the service user. Such ‘substitute decision making’ (Hope & Oppenheimer, 1997) takes into account what is known about the potential user’s prior wishes with 'advanced directives’ a huge aid to this requirement.

Most significantly, in cases of proxy decision making, the DHC Professional will want to establish the legal grounds for this i.e. does the carer have a Guardianship Order or have Enduring Powers of Attorney. Furthermore, any welfare decisions such as signing a contract for Telecare have to be carefully documented, as Councils have powers to supervise Guardianship Orders. In Scotland, in line with the letter and spirit of the 5 principles of the Adults with Incapacity Act 2000, such proxy welfare decisions have to be justified according to the following criteria:

- The welfare decision must represent the most beneficial option available at this time, having considered all the other options;
- Current and prior wishes of the end user must be sought if possible;
- The welfare decision must involve the least restrictive intervention possible;
- All possible communication channels should be used to ascertain the wishes of the service user ‘whether human or by mechanical aid… appropriate to the adult’. It is particularly noteworthy that such aids could include software products as in 'computer assisted reminiscence' (Astell, 2005; 2006).
- The views of relevant others have to be taken into account ‘as far as it is reasonable and practicable to do so’.

However, while there are stringent safeguards in place to ensure valid consent the DHC professional must also be aware of the possibility of other stakes in the decision-making process. These interests may not always prioritise the autonomy, beneficence and non-maleficence (Beauchamp & Childress, 2001) of the home service user with dementia. It is such influences that the next sub-section examines.

4.1.3 ‘Other Centred Design’ or ‘User Centred Design’: Who really benefits?

Ethical reflection by the DHC professional requires critical consideration of other forces behind the possible ‘technological push’ of assistive technological services for people with dementia:

‘... the very success of this [Assistive Technology] sector ... means that there is a risk that the momentum will be technologically driven ... the focus may be upon the acquisition and use of
assistive technology as a panacea - without proper consideration of the needs, preferences and lifestyle of some end users...Person centred approaches to the use of technology, consideration of ethical and legal issues and best practice may receive less attention...amongst hard pressed managers ... using it primarily to make budget savings and meet performance indicator targets’ Woolham (2006b:5).

The disinterested DHC professional may be aware that commissioners of Telecare services can be tempted to avail of bulk discounts or other 'sweeteners', so that service users can be matched to standard technological packages instead of the other way round. This caveat emptor and related ethical concerns can be linked to the critical sociology of healthcare technologies that unmasks the ‘technological imperative’ in relation to vulnerable service users. Few assistive technologies are morally neutral because they may have designers’ ‘pre- configurations’ of a standardized end- user (Woolgar, 1993 in Lehoux et al., 2004) ‘inscribed’ in them before production (Hyssalo, 2004). It is no surprise therefore that Lehoux et al.’s (2004) interview study of home healthcare technologies highlight major differences between the idealized ‘preconfigured user’ and real user experiences. From their study they note that,

‘While brochures highlighted all the activities made possible thanks to the technology, the interviews revealed the restrictions and constraints imposed on daily activities, and the grieving process the patients had to go through (for life prior to the use of technology).... Safety features that are supposed to be conducive to user autonomy were seen as part of a certain form of slavery to technology’ (Lehoux et al., 2004: 631).

Likewise, most socio-technical innovations are attended by utopian language and ‘spin’ that needs to be critically interrogated by the DHC professional. For example in the West Lothian Telecare programme, various vocabularies of ‘positive change’ abounded in its literature in advance of any empirical evaluation: 'a Technological innovation... a new approach to housing for older people... new models of care’ (Bowes & McColgan, 2003b). Such glowing endorsements also accorded with the publicity literature from the various project partners (e.g. the Tunstall Company which seems to currently enjoy market domination in the UK). At face value, such claims seem no different from... ‘the rhetoric of technologists generally who assure us that brave new technologies shall transform the ways we work, think and live’ (Hyysalo, 2004: 1). Arguably most of us as rational consumers are often immunised to such marketing messages. But there are particular ethical sensitivities linked to such claims for vulnerable users since their critical faculties can be impaired. As noted in the physical disability literature, vested interests can manipulate assistive technological services as a sop to distract disabled people from more valid personal and socio-political concerns (Roulestone,
Policy makers and services commissioners can make decisions more swayed by the ‘technological imperative’, the promise of rationalisation and a pervasively actuarial logic, than careful attention to potential service users’ needs, individually and collectively. Supportive neo-liberal discourses can promote the putative benefits of self-care and consumer empowerment, deploying a seductive 'win-win' logic, while conveniently overlooking the complex needs which a condition like dementia presents. It is no surprise therefore that Baldwin (2006) recommends a ‘proactive ethics’ for Telecare services, avoiding ‘reactive ethics’ to ‘technological push’, as noted in the ‘cautionary tales’ of the philosophy of technology generally.

Yet, if the dangers of the ‘technological imperative’ and its handmaid of service rationalization necessitate critical scrutiny, so too does the other extreme – the temptation towards ‘ludditism’ and ‘technophobia’. This is because the beneficial potential of some socio-technical systems can be foregone by resisting or rejecting them on inadequately informed grounds. For example, in relation to new technologies for dementia support, public media can circulate adverse representations of some kinds of ‘tagging’ for people with dementia (BBC, 2007). Other technologies with a more proven track record may be sidelined as a result and unfairly labelled pejoratively. Furthermore, such skewed representations of assistive technologies can be conflated with discriminatory views about people with dementia and older people in general. In the absence of any other informed sources, such biased discourses might prevail and inhibit better informed debate. This legitimate concern creates a strong ethical case for fuller informed discourse on the role of assistive technological services and Telecare for vulnerable service users such as those with dementia.

However, some of the more optimistic approaches in the sociology of technology, while rejecting technological determinism, emphasise the power of ‘relevant social groups’ in appropriating and promoting technologies (Oudshorn & Pinch, 2003). According to this perspective, technologies and their surrounding services offer ‘interpretive flexibilities’, thereby ‘carving certain paths of evolution’ to suit various user groups (Lehoux et al., 2004:620). Formal and informal carers who use Telecare services may be one such ‘relevant user group’. Home monitoring services in particular may be hugely beneficial to them as a care management tool. But there is a danger that carers’ agendas will dominate and the voices of people with dementia be marginalised. It is recently noteworthy how Tunstall, one of the world’s leading suppliers of Telecare technology, is targeting much of its publicity material on Carers, emphasising ‘peace of mind’ and security as benefits for them. It is also ethically significant that concerns about the over-reliance on proxy decision making by carers is still expressed in the literature on assistive technological services (Woolham et al., 2007; Robinson et al., 2007), despite the circumscriptions surrounding proxy
4.1.4 The Ethical Case for User Centred Telecare design

In relation to home healthcare technologies in general, Lehoux et al. (2004) criticise much rhetoric about ‘user centred design’ as merely tokenistic. In practice, they note that proxy users, usually company employees, are used to develop product prototypes, consultation with end-users only taking place at a much later stage. Finch et al. (2008) also criticise the relative absence of service users’ voices in the design of ‘telehealthcare’ systems. A similar lack of attention to older service users' voices is a common criticism of Assistive Technology design in general, with ‘user acceptability routinely assessed via proxy carer report’ (Robinson et al., 2007:390). One notable example is the frequent criticism by Occupational Therapists of the lack of ‘user centred design’ in installing stair lifts for older people (Doughty, 2007a). Such observations are all too common, despite the existence of good prescriptive models in the literature for Assistive Technology in general; the ‘Quebec User Evaluation of Satisfaction with Assistive Technology’ (QUEST) (Demers et al., 2002), ‘Contextual Usability’ (Nicoll, 1997 in Kinder, 2000) or the recently developed MDDS check-list for Assistive Technology (Sommerville et al., 2006; Sommerville & Dewsbury, 2007; Smarthinking, 2008). Nevertheless, we are fortunate in the field of dementia care that excellent studies exist for the applicability of stand alone technologies to dementia home care.

However, the same cannot yet be said with confidence about Telecare services because of their novelty. In the roll out of Telecare in the UK so far, a number of commentators lament how ‘user centred design’ -though common in policy rhetoric- is sorely lacking in practice (Loader et al., 2007). Instead Telecare services seem to be in danger of installing ‘standardised’ packages for end users without a thorough individual needs analysis (Percival & Hanson, 2006). Such concerns are particularly noteworthy from the Occupational Therapy community (e.g. Lyall, 2005), a profession which has championed the *sine qua non* of ‘user centred design’ in general (McCreadie & Tinker, 2005; Lansley et al, 2005; McCreadie et al., 2006).

As a result of the consensual ethical requirement to harmonise the principles of user-centred design with person centred care, the attention of the DHC professional is drawn to a frequently referenced tool for incorporating assistive technology into person centred care, Woolham & Frisby’s (2002:13) ‘Cyclical Assessment Model’:

*Assess the needs of the person with dementia*
Describe the living circumstances of the person with dementia
Analyse the needs of the person...
Identify the problems that need to be solved...
Identify potential technology and alternatives...
Consider ethical issues.
Prepare the care plan and arrange services
Recommend technology
Complete an ethical protocol
Chose solutions and decide...
Implementing the care plan...
Install the equipment and test
Arrange social response to alarm
User acceptance
Review
Reassess the person with dementia...

Some ethically significant elements of this assessment tool will now be illustrated in the following examples.

4.1.5 Examples: Ethical Dimensions of User Centred Design for People with Dementia

To culminate this Section 4.1 on user centred design to harmonise with person centred care, a number of practice examples illustrating ethical dimensions have been assembled. Though not networked applications, they are electronic assistive technologies with transferable lessons for ethical Telecare design for people with dementia.

As precursors to Telecare, stand alone technologies do not need to be interconnected but still can support 'safety, reminder and alarm functions' (Cash, 2004) as well as communication, recreation and entertainment benefits. The value of such ‘stand alone’ devices has recently been endorsed by NICE/SCIE, in their joint National Clinical Practice Guideline (No. 42) on supporting people with dementia. These lessons seem partly transferable to Telecare implementation because its building blocks have often been stand alone devices such as medication reminders, memo minds or bath level monitors. To illuminate ethical issues, two brief examples of stand alone technologies are now considered.

Example 1: ENABLE

The ENABLE Project (Bjorneby et al., 2004; Gilliard & Hagen., 2004) developed a suite of
household devices as cognitive and memory aids for people with dementia. This European collaborative project aimed to examine the usability and ethical acceptability of electronic assistive devices for home based people and their carers. Without denying the reality of a neurological or vascular impairment, ENABLE’s underlying philosophy was based on the ‘new culture’ of dementia support where,

‘...it is possible to see dementia as a disability where there are potential benefits to be achieved through supporting everyday functions, adapting surroundings, products and activities for the affected person’s interests and needs’ (Bjorneby et al., 2004:299).

Gilliard & Hagen (2004) have reported on a ‘cross national evaluation’ of ENABLE which involved extensive interviews with people with dementia, their informal carers, and professional support workers. These technologies have been thoroughly researched among the five partner countries in the programme. The products are listed as follows:

**Figure 12: Devices used in the ENABLE project.**

<table>
<thead>
<tr>
<th>Item</th>
<th>Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Devices to support memory</strong></td>
<td></td>
</tr>
<tr>
<td>Forget-me-not calendar</td>
<td>Used for time orientation to clearly indicate day, date.</td>
</tr>
<tr>
<td>Forget-me-not calendar adaptation</td>
<td>Used as above, with the addition of time of day</td>
</tr>
<tr>
<td>Locator for lost objects</td>
<td>Pressing picture button causes lost item to bleep. Stops when picked up</td>
</tr>
<tr>
<td>Bath water level and temperature monitor and controller</td>
<td>Automatically turns off taps if water level reaches a certain level, and keeps temperature within certain limits</td>
</tr>
<tr>
<td>Cooker usage monitor</td>
<td>Monitors thermal environment around cooker and turns off taps if user forgets</td>
</tr>
<tr>
<td>Medicine reminder</td>
<td>Automatically provides medication at set times</td>
</tr>
<tr>
<td>Remote day planner</td>
<td>A screen which displays tasks and activities for the day. This information can be input by the carer by phone</td>
</tr>
<tr>
<td>Voice reminder</td>
<td>A device which uses voice recordings to provide simple reminders, such as taking keys when leaving home, etc</td>
</tr>
<tr>
<td><strong>Devices to provide pleasure or comfort</strong></td>
<td></td>
</tr>
<tr>
<td>Picture gramophone</td>
<td>Do-it-yourself multimedia programme</td>
</tr>
<tr>
<td>My history device</td>
<td>PC with touch screen showing pictures of people and places with familiar voice narrative</td>
</tr>
<tr>
<td>Automatic bedroom light</td>
<td>Automatic table lamp, which turns on and slowly brightens when someone gets out of bed at night. The user can turn it off or it will dim slowly once the user is back in bed</td>
</tr>
<tr>
<td><strong>Devices to facilitate communication</strong></td>
<td></td>
</tr>
<tr>
<td>Pre-programmable telephone</td>
<td>Calls initiated by just pressing one large button containing a name or photo</td>
</tr>
</tbody>
</table>


Overall, people in the early stages of dementia seemed to benefit the most from ENABLE, as user habits could be established and entrenched. Gilliard & Hagen (2004) observed that because some of the ENABLE technologies needed a lot of input from the user, the more automatic and ‘passive’
devices were more successful:

‘Greater success for the person with dementia was achieved with products that required the least interaction such as the night and day calendar, a device that can be plugged in and left alone’ (Gilliard & Hagen, 2004:46).

For some devices, Gilliard & Hagen (2004) also noted how the role of carers was vital for motivating the user with dementia and for prompting them to gain optimum benefit. For example in relation to the key and item ‘locator’:

‘... the locator required new learning, but some people with dementia were able to use it independently. However, in most cases it was used by the carer’ (op. cit., 46).

More critically, in the case of the ‘medication reminder’, Gilliard & Hagen (2004) noted that its safer use was highly dependent on carer support:

‘In some cases, living together with someone was essential for the usefulness of a device. Examples were reported with the medicine reminder, where the person with dementia could hear the bleep, but did not understand what it was. Her husband’s hearing was impaired, but when his wife said she heard the bleeping he would know it was time for her to take the medicines’ (op. cit., 44).

However, the DHC professional will note that the ENABLE project has highlighted difficulties in balancing carer and user interests relating to new technologies. Carers may push technologies in the interests of ‘beneficence’ of the end user but this can undermine the autonomy of the end users themselves. The ENABLE evaluators suspected that in the Finnish study in particular, undue pressure may have been exerted on people with dementia to participate, since it was family carers who stood most to gain from the project (Bjorneby et al., 2004). Furthermore, give the high level of carer stress in dementia home care, professionals may collude with carers by pushing the technology as an ‘electronic anxiolytic’ for them, despite the legal safeguards on valid consent and incapacity which now exist under UK legislation.

Example 2: ‘At Home with AT’.

Dementia Voice expanded the ENABLE product suite for a field trial of other electronic assistive technologies in the homes of people with dementia. A multi-stakeholder evaluation of these products was produced (Cash, 2004; 2006). Similar to ENABLE, there was a strong emphasis on the user benefit of ‘low tech’ products. The overall objective of At Home with AT was to,

‘...explore the potential of existing low-key technological devices, which are readily available, to support people with dementia and their carers in their own homes’ Cash (2006:9).
Cash (2006) emphasises that these standalone items can be bought at the ‘DIY store end of the market’ and do not require connection with sophisticated electronics. Such items are also intended for a more ‘inclusive design’ market, helping to reduce the stigma of using prompting devices and short term memory aids (Fisk, 2001). The 7 devices used were selected according to the three main functions as set out in the table below. To these functions this author has added the column ‘Key Observations based on Cash’s Evaluation’:

As in ENABLE, the item ‘locator’ seemed the most popular device, given that misplacing items is a significant concern to both people with dementia and their carers. However it must be said that the locator was most successful where a carer supported its use. For example, one lady was able to operate the locator only when instructed over the telephone by her son. This observation is in line

<table>
<thead>
<tr>
<th>Function</th>
<th>Device</th>
<th>Description</th>
<th>The Author’s Key observations based on Cash’s Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety</td>
<td>Night Lighting</td>
<td>Activated by Passive Infra red (PIR) on bed exit</td>
<td>Usually used in co-residence situations or where a carer lives nearby</td>
</tr>
<tr>
<td>Safety</td>
<td>Magi plug in sink/bath</td>
<td>Lets excess water out of bath/sink</td>
<td>Seems a much simpler solution to water safety than other more sophisticated products.</td>
</tr>
<tr>
<td>Alert &amp; Alarm</td>
<td>Door alarm (Internal only)</td>
<td>Signals that a person has exited house.</td>
<td>Alarm not always heeded by user.</td>
</tr>
<tr>
<td>Reminder</td>
<td>Memo Minder</td>
<td>Selection of pre-recorded messages depending on where user is in house.</td>
<td>Only seemed to work with mild to moderate dementia as it causes confusion in more advanced cases.</td>
</tr>
<tr>
<td>Reminder</td>
<td>Locator</td>
<td>Commonly used items such as keys of spectacles are radio frequency tagged to allow location when corresponding icon is pressed on locator unit.</td>
<td>Sound level has to be checked with user. Most effective when carer supports its use, as found in ENABLE.</td>
</tr>
<tr>
<td>Reminder</td>
<td>Medication reminder</td>
<td>Bleeps at pre-set medication times and dispenses drugs.</td>
<td>Person with dementia needs to learn how to use, otherwise can be confusing. Ideally this needs carer support.</td>
</tr>
<tr>
<td>Reminder</td>
<td>Telephone with pre-programmed buttons or pictures.</td>
<td></td>
<td>Works well if picture is recognized, but may case confusion at later stages of dementia.</td>
</tr>
</tbody>
</table>

Based on Cash (2004: 9).
with Cash’s (2004) general observation that most of the stand alone devices were optimally effective, when backed up by informal carers. This is similar to the findings of the related ENABLE evaluation. Overall, what these studies are suggesting is that there is a high dependence on carers, for better or worse, for optimal use of the assistive technologies.

The DHC professional will therefore ask if the addition of Telecare overlay to this support mix makes any difference to the dynamic between independence, control and care for someone with dementia? This question will be addressed in the next Example.

**Example 3: Combining Telecare with other Assistive Technologies: The ‘Safe At Home’ Project for People with Dementia.**

This Example examines how the user centred design lessons from the existing vein of dementia home care technologies, can be applied to the development of Telecare services. The ‘Safe At Home’ project for home support for people with dementia grew out of Northamptonshire’s role in the ASTRID project (Marshall, 2000). The ‘Safe At Home’ project

‘...aims to use existing assistive and Telecare technologies to support people living with dementia, and their carers by using technology to compensate for disabilities arising through dementia and to manage risks that may jeopardise continuing independence’ (Woolham, 2006a:13).

The ‘Safe at Home’ project is therefore noteworthy in its dual role not just to minimise risk for home based users but also to promote rehabilitation, in line with recommended practice for mild to moderate dementia (Marshall et al., 2006). The DHC professional will note that a commitment to holistic assessment was fundamental, where ‘assistive and telecare technologies are only deployed following a thorough, holistic and person centred assessment’ (Woolham, 2006a:73). This resulted in creative person –centred customisation and meant that technological solutions could be simple; for example, the ‘magi plug’ could be preferred to more sophisticated smart home technologies for preventing flooding.

In the following case, a potential user rejected the proposed alarm system involving a standard door exit pressure mat. This preference, though apparently ‘unwise’, was respected but subsequent assessment illuminated this decision. It transpired that her dog, which the lady experienced as a deterrent to burglars, had recently died. This led to further negotiation and the tailored solution was a doormat that,

‘...when stepped on, activated a pre-recorded sound of a dog barking rather than an orthodox ‘alarm’ sound... the device therefore came to have two purposes... the ostensible
of acting as a kind of burglar alarm, as well as a surveillance device to enable action to be taken if the service user left home at an inappropriate time’ (Woolham, 2006a:32).

This example shows how ‘solutions’ have to be tailored to specific user requirements instead of the standardised solutions that Assistive Technology services are frequently criticised for. Such bespoke attention to user centred design meant that any pre-existing technological biases had to be interrogated as part of ethical practice. This accords with other service models of best practice in Assistive Technology design for dementia (e.g. Calder, 2006; Orpwood, 2007).

As part of the project evaluation, the ‘Safe at Home’ group was matched to an Essex comparator group. Woolham (2006a:64) claims that,

‘Members of the Essex Social Services Group were four times more likely to have left the community over the 21 month fieldwork period than Safe at Home users, and it was also clear that those from the Essex group were more likely to leave the community at an earlier stage’.

These claims are methodologically defended through the author’s account of careful study design where the two groups were ‘appropriately selected and well matched’ (op. cit: 64).

The ‘Safe at Home’ findings also suggested many benefits for informal carers. Carers reported improvements in such problem areas as interrupted sleep, coping difficulties and lack of respite opportunities (Carers UK, 2008).

The ‘Safe At Home’ case studies have underscored the centrality of person centred design, even if it requires a lot of time and effort. Yet some limitations must also be pointed out. Only a minority (13%) of ‘Safe at Home’ users had any Telecare connectivity which raises further questions about the ethical acceptability of Telecare services for people with dementia.

4.1.6 Going beyond the available evidence base for Telecare and dementia: Further Ethical questions.

The DHC professional will appreciate that the available evidence base can only take us so far in understanding the ethical implications of Telecare services. Further ethical issues need to be clarified relating to:

- The outcomes of Telecare services for people with dementia in terms of enablement or further containment;
- The outcomes for informal and formal carers and care relationships;
- The ethical dimensions of Telecare service configuration and its harmonisation with other formal services.
To address such questions, there is very little empirical material in the literature to date. Instead, most ethical reflections on Telecare services are speculative. In the speculative literature on Telecare related ethics, there is recognition that new networked technologies create issues that cannot always be addressed by the more conventional analyses of stand alone technological services. There are therefore calls for more empirical work. Pending the publication of such research, the literature used in this Thesis to address the remaining study questions is drawn from the following sources:

1. Pilot project studies (Waddington & Downs, 2005)
2. Sociological commentaries on Telecare per se (Dewsbury, 2007a) or related work on healthcare technologies (Lehoux et al., 2004)
3. Policy papers mainly supportive of Telecare (Audit Commission, 2004a&b; Wanless, 2006)
4. Small scale foresight studies. These consist of interview studies or Focus Groups, where participants are given vignettes about Telecare-related situations generating discussion about prospective ethical issues (Gilliard & Hagen, 2004; Laviolette & Hanson, 2006; Savenstedt et al., 2006; Rahimpour et al., 2007).
QUESTION 2: TO WHAT EXTENT ARE TELECARE SERVICES OFFERING ENABLEMENT OR CONTAINMENT FOR PEOPLE WITH DEMENTIA AT HOME?

Having looked at person centred design as a guiding ethical principle for dementia home care (DHC) professionals, the next set of issues explores the possible outcomes of Telecare services on end-users with dementia. Commentaries on the potential of Telecare often see such outcomes in terms of dichotomies such as ‘enablement’ versus ‘containment’ (Dewsbury, 2007a), and these concerns can be linked to sociological studies on the impact of home healthcare technologies generally. For example, in the Lehoux et al. (2004:631) study, ‘The devices we studied always both enabled and constrained the patient’s daily activities and broader lives’. The issue of ‘containment’ versus ‘enablement’ is of critical ethical concern to evaluating ICT services for people with dementia. This is because it is feared that Telecare services might be extending models of ‘controlled communities’ and electronic ‘warehousing’ by stealth into peoples own homes under a cloak of user empowerment:

‘Technology can be used to enhance the independence of someone with a failing memory to compensate for their disability and to help to maintain their health and well being ...It can also be used to control, or to contain ‘problem’ behaviour-usually for the benefit of someone else and not the person with dementia’ (Woolham & Frisby, 2002:16-17).

Likewise, the Alzheimer’s Society uses a bi-polar construct around enablement and disablement to frame the following caveat:

‘If assistive technology does not meet the individual needs and preferences of the person with dementia it may be ineffective or may even cause additional confusion or distress. Technology has the potential to disable a person with dementia as well as enable them’ (Alzheimer’s Society, 2007b:8).

Although it is recognized that such dichotomies can appear over simplistic, in the absence of empirical evidence, it is proposed that the dichotomy of ‘Enablement – Containment’ be used as the analytical axis, around which core issues in the literature cluster. Other related ethical concepts will then be gradually referenced to this main axis. The main ethical issues and tensions addressed in this Section 4.2 are thus outlined in the following table:
Figure 14: Contrasting possibilities about the ethical impact of Telecare services on people with dementia.

<table>
<thead>
<tr>
<th>OPPORTUNITIES: CLAIMS THAT TELECARE SERVICES ARE ENABLING</th>
<th>CHALLENGES: CLAIMS THAT TELECARE SERVICES PROMOTE CONTAINMENT.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telecare services may facilitate the maintenance of Homes as site of enablement.</td>
<td>Electronic Assistive and Telecare services may generate forms of ethically dubious containment due to:</td>
</tr>
<tr>
<td>Growing evidence for technology–enabled rehabilitation benefits for people with dementia.</td>
<td>• Risk due to technical unreliability</td>
</tr>
<tr>
<td>Telecare enables home safety, security and risk reduction, provided the constructions of risk are carefully negotiated with service users, carers and other stakeholders.</td>
<td>• Risk of over automation.</td>
</tr>
<tr>
<td>Lifestyle monitoring studies suggest people with dementia retain domestic and self-management skills, perhaps more than previously thought.</td>
<td>• Risk of social isolation</td>
</tr>
<tr>
<td>Increased transparency of the home can detect and prevent abuse.</td>
<td>• Creeping surveillance</td>
</tr>
<tr>
<td>ICT can promote collective ‘empowerment’ as noted in ITC support for collective advocacy in dementia.</td>
<td>• Behaviour modification by stealth</td>
</tr>
<tr>
<td>Although ICT solutions may substitute for some home care services, this may be welcomed by some people with dementia.</td>
<td>Panoptical Telecare can constrain people with dementia in terms of risk analysis.</td>
</tr>
<tr>
<td></td>
<td>Telecare services may become part of the ‘circuit of surveillance’ by the welfare state, monitoring performance of formal carers and checking informal carer’s eligibility to Carers Allowance.</td>
</tr>
</tbody>
</table>
4.2.1 Telecare Services and empowerment at home

This section examines the potential of Telecare for assisted independence and empowerment in dementia home support. The DHC professional will appreciate the psychological benefits to retention of home as a stable locus of control for older people with dementia, many of whom are subject to progressively disabling outer and inner losses (Cheston & Bender, 2003).

As one tool towards empowerment, there is a growing interest in designing cognitive prosthetics for various forms of cognitive impairment. A “cognitive prosthetic” may be defined as,

‘...any computer-based system that has been designed for a specific individual to accomplish one or more designated tasks related to activities of daily living (ADL), including work’ (Lynch, 2002 cited in Lopresti et al., 2004: 7).

In parallel with the literature on ‘environmental prosthetics’ for disability generally (Stokes, 2002), dementia-friendly homes can be designed for the safe performance of activities of daily living. Although Lopresti et al. (2004) claim that much more research needs to be done in 'matching' appropriate technologies to individual cognitive impairments, the occupational therapy literature already illuminates how assistive technologies can be sensitively customised for individuals and households. For instance, Wey’s case studies of safe cooking describe ways of ‘fitting the technology to the person, not the other way round' (Wey, 2006a: 208). His ‘smart’ cooking solutions seem more ethically desirable than commonly prescribed alternatives in home care assessments such as microwave ovens or 'meals on wheels'. Although it is tempting to recommend a microwave oven instead of a gas cooker for someone deemed to be at risk, the former carries its own risks for the user with dementia as Dunk & Doughty (2006) rightly point out – burning, scalding or putting unsuitable objects such as metals in the microwave. In addition, an over-reliance on 'meals on wheels' can mean the loss of significant shopping, meal planning and preparation skills. As a result, this kind of provision may be psychologically harmful for someone with dementia for whom self-catering, social role valorisation and hospitality expression might be vital components of self-esteem.

Deeper psychological benefits may also be possible due to the coherent and continuing 'practice of self' which activities of daily living enable. In the dementia literature, there is increasing focus on the 'primacy of practice' in maintaining a sense of self, thereby complementing the social psychological concepts of Kirkwood and Sabat. This means that what people with dementia themselves say and do is as vital a component of selfhood as socially interactive inputs:

'One of the most important properties that we have, the power to know ourselves to be the same being over time, depends on practice in the environment rather than conversation in
This development is also assisted by growing understanding of the neurophysiology of Alzheimer's disease and vascular dementias. This means that we are no longer justified in seeing all dementia as 'global intellectual decline' (Anderson, 2008), but that memory and cognitive losses are cerebrally localised and differentiated. For example, Anderson (2008) discusses mismatches between 'knowing what' and 'knowing how' domains of knowledge, due to differential declines in temporal and parietal associative areas of the brain respectively. For example,

'[...it is common to find people with dementia who can use a mug but not know what it is, or who know what it is but cannot use it]' (op. cit, 70).

Or, a man can use toothpaste for a perfectly executed shave without being able to differentiate between shaving cream and toothpaste. In reinforcing the 'practice of self' by capitalising on existing strengths and skills, appropriately tailored 'cognitive prosthetics' coupled with human resources, can contribute to supporting a vitally coherent and continuous self.

In addition, any assistive technological service which enhances home support as an alternative to institutional care can help to equalise power relationships with dementia home care professionals and may facilitate better partnership working with co-residents and informal carers. The question of home enablement naturally leads onto the next set of ethical issues about the potential of rehabilitation for people with dementia.

4.2.2 The case for technologically enabled rehabilitation for people with dementia

Rehabilitation is very much on the current empowerment agenda for people with dementia, noticeably advocated by people with dementia themselves (Friedell, 2006). This may be part of a renewed focus on recovery in the general mental health field noted by Adams (2008c). There may even be potential for technologically-aided 'remetia' (Kitwood, 1997), reversing some of the stepwise degeneration associated with vascular dementia in particular, though there is little if any evidence for this. Yet, none of this focus on rehabilitation is to deny that most dementias still have to be seen as progressive conditions.

In relation to cognitive rehabilitation (Clare, 2006), reminiscence software (e.g. CIRCA, 2008) can validate the unique biography of each individual and aid effective communication (Adsell, 2005; 2006). However, DHC professionals using reminiscence activities must be careful not to further 'contain' people in their past memories, since relating to older people as raconteurs of entertaining
recollections and as 'comedy fodder' for other audiences seems subtly ageist. As a form of service feedback, long term memory strengths can be valuably and sensitively blended with orientation to the present to elicit service users' views on home care and other services (Hughes & Baldwin, 2006).

Lifestyle monitoring systems, such as 'Just Checking' (Just Checking, 2009) if validly consented to, can be a useful source of objective data on patterns of home use. From a significant pilot study of 'Just Checking' in Warwickshire (Price, 2007b), the analysis of data on 'activities of daily living' has suggested that people with dementia are managing to self-care much more than revealed by conventional assessment and intermittent carer observation. This may be partly because people with dementia may under-perform when humanly observed, due to performance anxiety and others’ challenge to their suitability for 'staying put' if they are seen to fail. We are reminded that forms of 'learnt helplessness’ may be induced by the low expectations of others, as Kitwood (1997) points out in his condemnation of 'malignant social psychology'. People with dementia may be doing much better than hitherto realised when we leave them to get on with their usual comfortable home routines. In her questioning of the validity of conventional assessment such as 'Kitchen Task Assessments', Price therefore makes a case for the more 'objective' assessment benefits of a tool such as 'Just Checking':

'Assessments are carried out in an unfamiliar institution or by piecing together anecdotes from relatives and neighbours with short visits to a person's home where the very act of visiting will have an affect on the person. ...Once the visitors have gone they are back in charge and their activity charts show that they are active and purposeful when left to their own devices' (Price, 2007a).

Studies using ‘Just Checking’ are suggesting the continuance of ingrained abilities so that, for example, failure to recognise a loved one does not mean that other practical skills are lost:

'In one case the person with dementia was unable to recognise her daughter... Nevertheless, she was maintaining a very well-defined day and night time pattern, got herself up and went to bed, and prepared meals regularly, regardless of when home care visits were made' (Price, 2007b: 15-16).

Price (2007b) explains this phenomenon of deeply ingrained domestic skills in terms of 'situated cognition', where the home environment acts as a kind of external memory which cues and prompts to reinforce Activities of Daily Living:

'In the majority of cases... it [Just checking] has shown that people with dementia are maintaining daily activities, contrary to initial concerns and expectations... this ... encourages
families and professionals to step back and see what the person is capable of, and avoid intrusive and inappropriate interventions’ (Price, 2007a: 43-44).

Such findings, which further research could better illuminate, challenge our understanding of what differential memory loss in dementia means. Some domestic skill-sets may be left intact, despite significant losses in other domains. For the DHC professional, it gives a new impetus to 'building on strengths' as a realistic and realised goal (Alzheimer's Society, 2003).

The possibility of sustained home re-enablement for people with dementia can also be linked to the ‘expert patient’ agenda. In Finch et al.’s (2008) studies of how patients are being constructed through new ICT initiatives in healthcare, accounts about patients as ‘educated self mangers’ predominate. These new forms of ICT-enabled expertise democratize the encounter between ‘patients’ and professionals. Such possibilities are being embraced by growing numbers of people with early-stage dementia taking on the ‘expert patient’ role and sharing their insider accounts with peers and carers (Bryden, 2005; Alzheimer's Forum, 2008). Currently, there are calls in Scotland for more initiatives in information and support for ‘self care’ for people with dementia (Alzheimer Scotland, 2007). Assistive technology services such as Telecare may play a significant role in facilitating this trend.

Yet, the DHC professional will be aware that there are continuing debates in the literature about the ethical acceptability of rehabilitation for people with dementia, especially beyond the mild to moderate stages. While Wey (2006b) argues that forms of rehabilitation are possible at all stages, Orpwood et al. (2005) and Botsis & Hartvigsen (2008) would seem to disagree, preferring to avoid using dementia home support technologies where the user must learn new skills.

Finally, even if it were demonstrated that ‘dementia-friendly’ home technologies might encourage more ‘self care, the practices promoting such ‘independence’ by DHC professionals, could be oppressive of adults with complex needs, reflecting more of the neo-liberal pressures of self-help than genuine ‘person centred care’. Rather than the ideal ‘holding’ practices for ‘positive person work’ recommended by Kitwood (1997), technologically-aided practices could therefore contain people with dementia in subtly oppressive ways, under the cloak of user ‘empowerment’.

4.2.3 Telecare, home safety and risk for people with dementia

One of the undoubted benefits of Telecare services seems to be enhanced home safety. The names of the main Telecare projects in the UK are quite telling; West Lothian’s ‘Home Safety Service’
(West Lothian Council, 2009) and Northamptonshire’s ‘Safe at Home’ (Northamptonshire County Council, 2001) service for people with dementia. In addition, the empirical work carried out by Bowes & Mc Colgan (2006) highly supports the safety benefits of Telecare, coupled with reassurance and peace of mind for informal carers. This benefit is exemplified in the following account comparing ‘pre-technological’ experiences with current views of Telecare service users:

‘...Half of the respondents explained that they had previously experienced falls at home, and saw the technology as being particularly important to safeguard them on future occasions. They described pre-technology experiences such as having been stuck in the bath for three hours, or falling in the bedroom and having to sleep on the floor until help came in the morning’ (Bowes & McColgan, 2006).

The DHC professional will acknowledge that due to progressive cognitive impairment, many people with dementia will present specific home and personal safety concerns. Even those highly critical of the ‘old culture’ of dementia care -with its tendency to institutionalise risky behaviour-present a list of common domestic problems for people with dementia as:

- Failure to switch off domestic equipment
- Remote supervision...
- Wandering and/or way finding...
- Risks of falling/disequilibrium...
- Inability to call for help...


Each of these dementia-related challenges can now be matched to ‘safeguarding’ solutions from Telecare services which seem to provide better protection than conventional community alarms which have pendant alarms or pull-chords as service interfaces. Accordingly, in making a case for the enhanced safety features of Telecare, Doughty (2004) discusses some of the limitations of conventional community alarm systems for older people as follows:

- Poor pendant-wearing compliance;
- A service user is unable to activate the alarm if fallen and too far away from a pull cord;
- Declining sensory abilities can mean insensitivity to hazardous smells, smoke or noises.

For instance, DHC professionals should note that pendant use is one of the least dependable community alarm technologies. In a Telephone random survey of general needs community alarm
users, only 21% said it was ‘around my neck’ (Blythe et al., 2005). All the other locations seemed inaccessible were the respondent to fall. This problem of wearing-compliance could be further exacerbated for someone with dementia. Furthermore, cognitive impairment could result in a complete unawareness of a hazardous home situation or an inability to articulate any urgent safety concern.

Future developments in ‘voice recognition’ technology may provide a more appropriate substitute than pendant technology so that Telecare alerts may be activated by key words like ‘help’ or from the distress tones of the user (Tavani, 2004). At present such ethically ideal artificial intelligence applications are not commercially available. However, a range of Telecare packages are now deliverable which can overcome some of the communication barriers of the cognitively impaired home user. These consist of networked sensor technologies such as intruder alarms, smoke or flood detectors for a range of predefined home hazards. In principle, their linkage to a Telecare Response Centre enables a fast-accurate response since the correct identification of a home hazard can be critical for a vulnerable user with cognitive or communication impairment. In addition, the minimal requirement for user interaction, avoids excessive cognitive and emotional demands on the service user with dementia:

‘The significant benefit of telecare for a person with dementia is that many devices are passive so the individual does not need to remember where they are or how to use them’ (Cash, 2003 cited in NICE/SCIE, 2006:190).

The selection of the right kinds of Telecare sensor technologies for people with dementia has therefore to be subject to a thorough risk assessment by the DHC professional, as part of holistic assessment (Manthorpe, 2004). To more fully illuminate the ethical dimensions of Telecare and home safety, a full consideration of risk now follows.

4.2.4 Risk and dementia care.

There is a basic quantitative understanding of risk as, ‘The product of the probability and consequences (magnitude and severity) of an adverse event’ (Bradbury, 1989 cited in Adams, 2001). This model can contribute to ‘actuarial risk assessment’ (Cree & Wallace, 2005) in healthcare, if enough is known about the risk patterns of sub-populations such as people with dementia. In the future, statistical analysis could be carried out on anonymised Telecare data identifying risk patterns and their correlations with different ‘stages’ and types of dementia. Indeed
one of the goals of the Alzheimer’s House studies (Serna et al., 2007) seems to be to detect correlations between the home users’ error rates in carrying out ‘Activities of Daily Living’ (ADLs) and the ‘stages’ of Alzheimer’s disease. This could create a set of individual predictive risk assessment tools and enable the customisation of technologies to different service users. However, in the meantime, the DHC professional is more likely to need qualitative multi-stakeholder approaches to achieve a comprehensive risk assessment. But how can this be done in an ethically acceptable way without viewing people with dementia as merely incarnations of risk variables (Cree & Wallace, 2005)?

Official policy correctly recognises the ‘rights’ of people to take risks, such as in the ‘National Service Framework for Older People’ (Department of Health, 2002). The DHC professional will recognise that the right to ‘positive risk taking’ (Morgan & Wetherell (2004) in Adams, 2008f) is ethically defensible for all service users including those with dementia. For any human being, risk taking is part of the ‘practice of the self’ (Cree & Wallace, 2005) and arguably, there can be no human flourishing without it (Bynum, 2006). We must therefore recognise that the concept of the ‘dignity of risk’ is as applicable to people with dementia as to other adult service users (Gordon, 2000). This may be defined as,

‘... the placement of ‘Greater value on respecting the individual’s right to decide – even when the person’s choices may seem foolish to others – than on protecting the “best interests” of the individual’ (Hommel, 1996 cited in Gordon, 2000:63).

Yet, the cognitive impairment of progressive dementia is reasonably understood to compromise the status of people with dementia as reliable ‘rational risk assessors’ (Manthorpe, 2004). This necessitates frequent dependence on significant others in negotiating personal and home safety concerns, even where an adamantly independent service user lives alone. Comprehensive risk assessment for people with dementia therefore usually involves multi-stakeholder participation, as illustrated in the ASTRID guide to ethics for dementia-friendly technology. The ‘3P’ model proposed by Marshall (2000) has been developed with people with dementia themselves and their carers (Marshall, 2000:43-45). The model draws on the psychiatric framework of Hope & Oppenheimer (1997), using the interactive triad of ‘principalism’, ‘perspectivism’ and ‘casuistry’.

According to Marshall (2000), the ‘3Ps’ are,

1 Perspectives of all the main stakeholders;

2 Principles of respect ‘autonomy, beneficence, non-maleficence and justice’;

3 Paradigms involving casuist analogies with other service users such as younger people with
learning disabilities to tease out comparisons and contrasts (E.g. would we give this technological service to a younger person with brain damage? If not, why not?).

Hughes & Baldwin (2006) commend ‘perspectivist’ approaches because they link with the good practice strands in 'person centred care’ generally through ‘empathic understanding’, ‘hearing the voice’ of the service user and ‘supported decision making’. This ethical imperative is also reinforced through UK law reform on capacity, where we must try using whatever communication channels are available, to involve people in decisions concerning them.

Yet 'perspectivism' around risk often seems far from harmonious since risk negotiation exposes the 'ethical fulcrum' frequently encountered in dementia care and social work generally – between autonomy and protection for vulnerable services users (Waterson, 1999; Manthorpe, 2004). As a result, DHC and other professionals, home service users and other stakeholders may not construct risk in the same way. To this end, Clarke (2000) has studied varying constructions of risk in dementia home care from different stakeholder perspectives observing that,

'... Professionals may emphasise the physical domains of risk identification... People with dementia however may emphasise biographical domains of risk such as loss of self-identity... family carers may emphasise interpersonal domains of risk such as the loss of a life partner' (op.cit., 84).

Such varying stakeholder perspectives are very noticeable in research on falls (Ballinger & Payne, 2002; Ballinger & Clemson, 2006). The researchers found that some older people may want to avoid the stigma of being seen as frail or vulnerable as this could increase the likelihood of alarmist reactions and the pressure of unwanted service referrals. Given the different constructions around risk, Manthorpe (2004) therefore stresses the need for sensitive negotiation towards the ideal ethical goal of consensus:

‘Risk needs to be named and its dimensions explored through discussions with people with dementia, their carers and a range of Professionals. Conflict is inevitable as individuals will pitch the fulcrum between independence and protection in different places’ (ibid, 148).

In addition to the above considerations about risk construction, the DHC professional will need to be aware of the following caveats:

- In healthcare and social work generally there are ongoing tensions between balancing needs assessment and risk assessment (Waterson, 1999), professional work with dementia being no exception. In some professional assessments, there is the danger of a ‘perverse incentive’ to exaggerate risk for someone with dementia in order to secure finite resources. In addition, constructing accounts of vulnerable service users in terms of risk, allows home
care professionals to steer a safe course and give litigation-proof accounts of their actions (Adams, 2001).

- Highlighting risky behaviour can reinforce ageist stereotypes in care planning for older people with dementia. Such subtle oppression can be internalised, posing psychological risks to self-esteem (Cheston & Bender, 2003). As a result, other relevant goals, strengths and needs necessary for holistic assessment, may be marginalised (Ray & Phillips, 2002).

- Opinion differences between professionals about risks to service users can also expose some deeper fault lines in collaborative working. This is because different professions will have tribal loyalties, different value bases and organizational cultures with underlying competitive agendas to self-maximise scare resources (Glasby, 2007).

Acknowledging that varying constructions of risk exist for different stakeholders, does not mean that all risks are imaginary. Inattention to obvious risks can have serious consequences for individuals with dementia, their households and neighbours and perhaps provides grounds for negligence litigation. There are well developed Telecare solutions for various types of risk if such packages are validly consented to. But the DHC professional might well ask, if Telecare as a socio-technical innovation might itself be creating new forms of risk for the home based user with dementia (Beck, 1992)?

4.2.5. Telecare services as creating new forms of risk?

The DHC professional will understand that assistive technological services are not the only way of protecting people from harm, but such interventions will inflect the nature of risk in new ways. From the small body of empirical work and the foresight studies to date, some possibly salient aspects of Telecare-related risk have been highlighted as follows:

- Risk and technical unreliability
- Risk and over automation
- Psychological risk
Risk and technical unreliability

At a minimum, technologies for home safety need to be highly ‘dependable’ otherwise they may do more harm than good (Dewsbury, 2007a). Similarly, Woolham & Frisby (2002) claim that technical unreliability can easily lead to ‘disenchantment’ and possible rejection of any assistive technology. This applies to both the technologies per se and the support services in which they are embedded.

It is significant that the ENABLE trials of assistive technology for dementia were hampered somewhat by the frequent unreliability of the tested devices which generated unacceptable stress levels for the users with dementia and their carers (Bowes, 2007). The following ethical caveat in terms of ‘do no harm’ or 'non-malificence', is therefore highly pertinent:

‘Avoid frustrating users due to upkeep needs of technology or its complexity, i.e. frequent battery changes to enable the components, daily resetting of the system or other burdensome demands requiring elder or other family involvement’ (Mahoney et al., 2007: 224).

Though these lessons would appear to have been taken on board by product designers, reports of technical unreliability still crop-up in the general literature on assistive technology for dementia support. For example, the ‘technical unreliability’ of currently available electronic medication dispensers (Woolham, 2006a) and 'incontinence detectors' (Askham, 2006) have been noted.

However, it must be said that one advantage of Telecare is that many technical faults or power failures can be remotely monitored and Telecare operators can activate prompt responses to these.

But a frequently encountered problem by Telecare staff is the service user who frequently plugs out the equipment’s power-supply as part of a night safety routine and the communication challenge this presents for restoring power. This is encapsulated in Coward's (2007) humorous article in The Guardian on his mother's Telecare service:

'... She has gone round, turning off every plug in sight, the old habits of frugality thereby prompting a message at their [Telecare] end that there has been an entire system failure. You have to feel proud of her. Almost immediately she's found a novel way of testing the system.'

More seriously, technical risks are posed by the frequently noted tendency for people with dementia to 'fiddle' with domestic technologies, necessitating careful attention to tamper-proof design (Smith et al., 2007) such as covered thermostats and locked socket covers (Dunk & Doughty, 2006).

Even more critical safety concerns arise when the technology is mistaken for something else. The following observation therefore provides a useful cautionary tale:
One person inadvertently destroyed medication dispensers by putting them in a microwave oven. The rounded shape and plastic surface may have resembled a 'splatter guard' or lid top that might be used to heat food in a microwave' (Woolham, 2006: 32).

Furthermore, because Telecare is a socio-technical service, inadequate service responses may be far more harmful than device faults or product misuse per se. The author’s personal experience as a Telecare Operator shows that users are often highly dissatisfied with false alarms, alerts and lights flashing unnecessarily and 'check phone calls' at unsociable hours. Such intrusiveness seems an additional imposition on people with dementia who may be unaware of their Telecare service in the first place, even assuming valid consent has been obtained. The DHC professional is therefore reminded that it is often perceived inadequacies in the surrounding service infrastructure that can lead to difficulties and rejection of Telecare services (Demers et al., 2002).

Risk and excessive automation

Mahoney et al. (2007) warn that users can over-estimate the capacity of healthcare monitoring technologies, reducing their normal vigilance about home and personal safety. ‘Smart’ technologies can even be invested with magical powers so that, 'the technology may imply to the participant that “someone is minding the store”' (Mahoney et al., 2007: 221). As smart technologies become more sophisticated, the ‘autonomy-automation ratio’ (Macieuszek, 2005) is set to become a more significant ethical issue in coming years.

Since home automation can reduce task demand (McCreadie & Tinker, 2005), risks of irreversible skill and role losses for someone with dementia are possible (Siotia & Simpson, 2008). The DHC professional needs therefore to carefully anticipate how services such as Telecare might de-skill the end user with dementia (Calder, 2006). This is because technological over dependence (e.g. automatic shut-off taps when a bath is full) can cause reductions in normal risk-avoidance behaviour.

It is also observed that functions of the human self are increasingly expressed in ITC related terms, 'so that the human person is increasingly seen as an ‘information processing engine’ (Tavani, 2004). This view of humanity may pose specific psychological risks for someone with dementia leading Baldwin (2006) to ask,

'... to what extent is the Self reconstituted through living with ubiquitous computing where
technology is attributed ‘the right to drive by itself the way in which certain aspects of everyday life are lived...’ (op. cit., 56).

There is a related danger that the evolution of forms of ICT-enabled home support for people with dementia may mean that their condition is viewed solely in terms of ‘information processing deficits’ (Cheston & Bender), to be remedied with ICT-enabled prosthetics (Lopresti et al., 2004). This is because ICT seems to privilege forms of rational capacities over other human capacities, subtly equating full personhood with the rational self. As a result,

‘...what it is to be a person comes to be defined in terms of those capacities... this ‘technologising’ of the self can help explain the hyper-cognitive society ...as devaluing people with dementia...’ (Baldwin, 2006:55).

As an ethical caveat, in our cultural bias towards ‘cognitive citizenship’, we risk devaluing the enormous citizenship contributions people with dementia can make. The following observation seems therefore particularly poignant and ethically salient:

'I am not sure I would hope for a world without dementia, for in a world without dementia we would be without the ones who have taught us that remembering and planning and naming and knowing are not the key activities of human life, but rather that feeling and being and touching and singing have enormous riches and depths that we are often too busy to relish in our race to rationality' (Killick & Allan, 2001:62 cited in Friedell, 2006:75-76).

Risk and domestic visibility

Various psychological risks have been highlighted in the general literature on assistive technologies. While good practice in dementia design is to recommend ‘unobtrusive’ devices (e.g. Orpwood et al., 2005), the visibility and audibility of some Telecare devices can impact on the home user's self-image, given that a home can be experienced and displayed as a ‘symbol of self’ (Heywood et al., 2002). In this regard, some of the general literature on domestic consumption is worth noting which compares the psychosocial symbolisms of ‘anxiety goods, status goods, and prestige goods’ (Antonides & van Raaij, 1998). For example, 'smart homes' (Pragnell et al. 1999) with their conspicuous consumer ‘cachet’ can boost the self-image and prestige of occupants. In contrast, the visibility of ‘prescribed care technologies’ such as alarm pendants or fall–detectors, can carry a ‘dependency stigma’, possibly transmogrifying them into ‘anxiety goods’ for the home user (Gitlin, 1995; Tinker et al., 2004; Beech & Roberts, 2008). There may also be social pressures from significant others to make the use of assistive technologies accountable in some way and this
could be additionally distressing for someone with dementia. As a parallel case to dementia, Gitlin's (1995) study on assistive technological acceptability found that,

‘...Stroke patients ... expressed greater negativity toward their disability and the devices they had been issued’, since their ‘prescribed’ assistive technology seemed to symbolise for them ‘lost function and abilities’.

Though people with dementia may be more cognitively impaired than other people, this does not diminish their sensitivity to technology and self-image. It is their possible concerns about the changed ‘gaze’ of significant others to them, whether real or imagined, that is ethically significant (Lehoux et al., 2004). The ethical proviso for service designers and commissioning DHC professionals is therefore to be sensitive to the possible symbolic dimensions of any (electronic) assistive technology, lest it be seen by end-users as a ‘badge of disability’ (Brownsell & Bradley, 2003). The upshot of these ethical considerations is that at least two progressive possibilities in dementia-friendly design should be considered by the DHC professional towards the goal of ethical acceptability:

- At an individual level, a design can double up as something more acceptable to the end user. For example, a personal alarm trigger can now be re-configured as a watch or piece of jewellery as in the ‘Vega Bracelet’ (Tunstall, 2009). Notably as an example of ‘inclusive design’ (Fisk, 2001), the aesthetic appeal of the ‘Forget me not’ calendar as a nice picture in the ENABLE project also meant that,

‘Many participants welcomed this particular product into their home... and it did not reveal to visitors that it was a device to remind them of a memory problem’ (Gilliard & Hagen, 2004:46).

- At a systemic level, de-stigmatising dementia as far as possible should be one of the ethical goals of overall service design (Marshall & Tibbs, 2006). In this regard, universalising the ‘Home Safety Service’ in West Lothian can therefore be seen as ethically progressive since ‘...mainstreaming may prevent some of the stigma attached to dementia ... by making protection against some key risks normal’ (Bowes & McColgan, 2006).

**Risk and home privacy**

There are undoubted possibilities noted in the literature about Telecare services enhancing healthcare assessment and allowing more proactive interventions (Audit Commission 2004a;
Wanless, 2006). Yet, it has to be acknowledged that the most significant ethical concerns in the literature relate to intrusive lifestyle monitoring. Heywood et al. (2002) commenting that ‘the notion of alarm systems can evoke images of “Big Brother”’, caution that,

‘... If doubts were felt about alarms controlled by the individuals themselves, [as in Sheltered Housing] what will people feel about mechanisms that record every visit to the toilet?’

It is similarly noteworthy that the ENABLE project on standalone technologies rejected any surveillance function as an unwarranted intrusion on privacy:

'In designing the ENABLE project the aim was not to include technology that represents surveillance and monitoring of a person’s functions and activities’ (Bjorneby et al., 2004:301).

When considering the commissioning of a Telecare package, the DHC professional will be aware that Telecare services can draw attention to vulnerabilities that cannot always be contained within the four walls of the home. The audibility and visibility of some forms of Telecare can attract negative attention. Paradoxically, an electronic safety net for dementia might therefore communicate the occupant’s home management difficulties in socially undesirable ways. For instance, too many audible smoke and gas alarms, even if networked to Telecare, can be socially discrediting if they frequently communicate to neighbours a home occupant’s diminishing skills. Accordingly, Calder (2006) in her report on the ‘South Lanarkshire Dementia Technology Initiative’ makes some relevant points in relation to gas safety:

‘The management of gas has proven to be a challenge in that there are a range of devices available but often when they are applied it only highlights the persons vulnerability if a relative cannot offer a ‘social response’ and can cause panic among the wider community when gas suppliers are being called to attend to a person’s home on a regular basis’ (op. cit., 31).

This is more seriously relevant if the service user lives in a block of flats where common home hazards can pose additional risks to neighbours.

**Risk and Personal Privacy**

The DHC professional will be increasingly aware of Telecare services that can monitor home users' vital signs or lifestyle patterns. Only designated professionals, Telecare staff and informal carers can access the resultant personal data. Yet, these services still require sensitive attention to the ethical boundary between monitoring for well being and respecting personal privacy. For instance, bodily hygiene issues are sensitive as they revolve around questions of intimacy and dignity. As an
example, the management of single or double incontinence is highly challenging in dementia home care. There are enuresis sensors on the market for night time care which can first alert the end user and then a carer if a problem persists. However, these sensors were found to be practically and ethically problematic in the ‘Safe at Home’ Project for people with dementia. As a result, a non-technological service solution was chosen so that,

'... though it was possible for the project to access ‘continence sensors’ to alert a carer to bed or chair wetting, it was agreed that referral to a specialist continence advisor was a more appropriate course of action to enable treatable causes to be identified' (Woolham, 2006a:300).

As part of Telecare in its broadest sense, ‘Telehealth’ can be used to provide valuable feedback for such illnesses as diabetes since the smart home system can interrogate the user about his/her health management and provide forms of customised coaching (Botsis & Hartvigis, 2008). Although some people with dementia will be unaware of any ambient home technologies, we cannot assume that this is always the case especially for early stage dementia. Instead people’s awareness may be misinformed or controlled for dubious reasons. Such technology could also be used as a form of behaviour modification, even for such ethically desirable goals as medication compliance, because people can imagine they are being checked on. As Laviolette & Hanson (2006) observe about a potential Telecare user:

‘He mentions in relation to his awareness of his weight problem that the telecare system will hopefully allow him to become more diligent about his diet, needing an outside incentive to help regulate what he does, like ‘peer pressure’ or something.’

The following cartoon well illustrates this point:

89
This issue of 'creeping surveillance' connects to deeper sociological questions about the 'panoptical' nature of knowledge/power (Foucault, 1977) which seem particularly relevant to Telecare services for people with dementia.

The panoptical risks of Telecare: Neo institutionalisation for people with dementia?

The notion of the 'panopticon' arises from the prison structure proposed by Jeremy Bentham where asymmetrical surveillance by a prison guard meant that inmates did not know when they were being watched, having only a generalised awareness of being monitored at any time.

'Power should be visible and unverifiable ...the inmate must never know whether he is being looked at at any one moment; but he must be sure that he may always be so' (Foucault, 1977: 201).

According to Foucault, this uncertainty internalises a sense of self discipline in those so viewed,
ensuring compliance with disciplinary regimes. In relation to Telecare, such a panoptical system might create the impression in vulnerable people that they are being watched or listened to, whether or not this is objectively the case. Assistive Technological services such as Telecare can therefore raise concerns about imagined ‘eavesdropping’, similar to those noted in studies of Sheltered Housing tenants (Percival & Hanson, 2006; Laviolette & Hanson, 2007). Similar anxiety has been noted in the ACTION study (Magnusson & Hanson, 2003) of care videophones, though reassurance was provided to end users that they were not being intermittently or continuously watched. Despite assurances, problems of imagined intrusion, auditory or visual, can be problematic for cognitively impaired people. This is why some Telecare services are clearly unethical for people with dementia who experience delusions or hallucinatory symptoms (Serna et al., 2007).

However, the notion of the panopticon as an ‘all seeing eye’ needs to be qualified in relation to Telecare. In reality, kinds of video monitoring seem rare in Telecare applications, with the exception of the interactive video services of ACTION, noted above. Even prototypical technologies for video monitoring for medication compliance (Smith et al., 2007) seem far removed from commercial availability. The ‘axial visibility’ of full video monitoring could rarely be ethically acceptable in any case, unless some kind of negotiated ‘frosted glass’ imaging is used (Centre for Usable Home Technology, 2008). What Telecare instead does is analyse data ‘imagery’ of home based lifestyles and ongoing health status as a form of ‘dataveillance’ (Dataveillance, 2008).

This notion of the panoptical threats of Telecare connects with ethical concerns about ‘surveillant practice’ in welfare services generally. This growing awareness is driven in part by concerns about an evolving ‘Surveillance Society’, which increasingly allows service providers to ‘probe behind the front door to discover what lifestyles obtain’ (Lyon, 2001:7). This can be linked to a social stratification agenda, because panopticism acts like a discriminating ‘naturalist’ (Foucault, 1977) making it possible to ‘to classify, provide typologies, draw up differences and similarities amongst patients [sic]’ (Laviolette & Hanson, 2006:39). Garrett (2004) warns that the growing capacity of this ‘disciplinary gaze’ to colonize hitherto private spaces, can create new ‘marginalia’ of disadvantaged groups. Could people with dementia be victims of such a trend?

It is what Telecare services can do with peoples data traces and data ‘shadows’ that conjures up the worst case scenario of ‘old culture’ wine in new wineskins:

‘...One can observe from the tower [Telecare control centre]... the small captive shadows [lifestyle data] in the cells of the periphery. They are like so many cages, so many small theatres in which each actor is alone, perfectly individualised and constantly visible.... He [sic] is seen but does he not see; he is the object of information, never a subject in
communication... ‘(Foucault, 1977:200).

In relation to people with dementia at home, the panoptical threat of Telecare seems therefore its capacity to classify individuals according to their 'risk' characteristics, containing them in 'safe' electronic 'cells' of 'exile enclosure' (Foucault, 1977). Through ICT-enabled practices of risk segmentation, victimized sub-populations of people with dementia might emerge who are continually 'identified, registered and managed by medication and surveillance’ (Cree & Wallace, 2005:125). The resultant extreme dystopian scenario is that people with dementia could become human-machine hybrids or 'cyborgs' positioned in a Telecare 'architecture whose basic modes of operation are probabilistic and statistical’ (Haraway, 1997 in Kirkpatrick, 2008: 97). As a result, people are indeed individualised, not as the 'subjects of communication’ required by the ‘new culture', but as ‘objects of information’ (Foucault, 1977). Thus through the electronic 'gaze' (Sinha, 2000) of Telecare, the ‘old culture’ of dementia ‘care’ could resurface by stealth through new models of home-based containment.

Yet, it must be acknowledged that a limited negotiated panopticism might be ethically acceptable if it profiled areas of continuing strengths as well as weakness, to promote 'positive person work' (Kitwood, 1997). This is because of the evolution of technological systems such as ‘just checking’ which seem to highlight continuing domestic skills in someone with dementia (Price, 2007b). Any ethical concerns about the electronic cocooning of people with dementia must also be balanced by more positive global trends. New surveillant technologies can also allow different 'circuits of surveillance' (Heaton, 1999) to operate in society, as self-empowering practices by different sub-groups. As part of the growth of ICT use by people with dementia, we may see the growth in such applications which monitor service quality and hold service providers to account. This is because as Foucault claims, ways of resisting real or imagined surveillance are also observable in reactive social formations, similar to the operation of Newton's 'Third Law'. For example, there is growing sociological interest in ‘sousveillance’ (Mann, 2004; Laviolette & Hanson, 2007) as a form of ‘reverse surveillance’. This is generally taken to mean citizenship activities of ‘watching from below’ in contrast to ‘watching from above’; consumers photographing or recording service providers, ordinary citizens photographing police with mobile phones and disseminating their coverage so that the powerful can be observed ‘backstage’ and off-guard. The future implications for Telecare are only speculative but service users with early-stage dementia and their advocates could challenge the ‘expert’ interpretation of their own healthcare data. Through new forms of ICT-enabled organisation, we may witness radical movements challenging prevailing orthodoxies.
This may parallel anti-psychiatric movements (Kirkpatrick, 2008) and the ‘Independent Living Movement’ which has radically contested some forms of ‘care’ as covert control (Reynolds & Walmsley, 1998).

4.2.6 Example 4: Ethical issues around Telecare and ‘wandering’

The challenge of ‘wandering’ and possible solutions to it brings together some of the tensions around enablement and containment, coupled with conflicting 'old culture' and 'new culture' practices relating to dementia support:

‘... Technology can offer the constraints of the institution within the community, replacing locked wards and sedation with tagging bracelets and global positioning systems... Yet the issue is complex as advocates for tagging in dementia care argue that, far from reducing personhood, electronic tracking systems both promote and maintain it’ (Bail, 2003).

The DHC professional will be aware that issues around ‘tagging’ and ‘tracking’ are probably the most controversial in the general media coverage of assistive technologies for people with dementia who 'wander' (BBC, 2007). Yet, it seems ethically unacceptable to pathologise all walking by someone with dementia as 'wandering' (Mc Shane, et al., 1994). Walking may not be problematic unless the person cannot find their way home or is at risk from hypothermia or adverse weather conditions. But this should not downplay the real risks and dangers of unsafe walking, estimated to occur in anything between 15% and 60 % of people with dementia (Alzheimer’s Society, 2007b).

Although the term ‘wandering technology’ is still frequently used, it is increasingly felt in ‘new culture’ circles to be an unacceptably loaded term. As a result, a more welcome neutral description is provided by the Alzheimer’s Society's (2007b) term, ‘Safer Walking Technology’. The issue of ‘safer walking’ highlights the often delicate balance between care and control when supporting vulnerable people, creating tensions about balancing individual autonomy, non-maleficence and beneficence (Beauchamp & Childress, 2001). But first of all, it must be noted that some people with dementia are appreciative of the possible benefits of safer walking technologies, as the following interview extract suggests:

‘There are situations where people like us might benefit. It's happened to me maybe twice in the last few years - I can be walking along on my own and the shutters come down and I just can't remember where I am. I wouldn't mind wearing something like a watch, something like that, in that kind of situation' (Alzheimer's Society, 2007b).

Such receptivity to technologies by people with dementia themselves, has influenced the recent decision by the Alzheimer's Society to give qualified approval to 'safer walking technologies',

93
subject to careful person-centred assessment.

The DHC professional has to ensure that before considering any ‘safer walking technology’, every attempt must be made to understand the unique triggers to ‘wandering’ for that person (Marshall & Tibbs, 2006). According to an ‘Ethics of Compassion’ perspective (Hugman, 2005; Hughes & Baldwin, 2006), carers and professionals therefore ought to try to understand the unique motivations for ‘wandering’, developing negotiated solutions if possible, such as by using the ‘ABC’ (Antecedents, Behaviour, Consequences) approach of cognitive behavioural therapy. This is because some ‘challenging behaviour’ by people with dementia can be understood as a communicative attempt, so that ‘wandering’ can often be defended as ‘pottering with a purpose’ (Mental Welfare Commission for Scotland, 2005).

In considering any ‘safer walking technology’ in a home care package, the DHC professional should weigh up the risks and benefits of such technologies, using such aids as the 5 Principles of the Adults with Incapacity (Scotland) Act, recommended by the Scottish Mental Welfare Commission's guidelines on ‘Wandering Technology’. The 5 principles are cited as follows:

1. The intervention must be of benefit that cannot be otherwise achieved
2. The intervention must be the least restrictive in relation to the person’s freedom in order to achieve the desired benefit
3. Take the present and past wishes of the person into account
4. Take the views of others into account, in so far as is reasonable and practical
5. Encourage the person to use existing skills and develop new skills

(Scottish Mental Welfare Commission, 2005:4-5).

Principle 2 is a reflection of the ‘Right to Liberty and Security’ (Article 5, Human Rights Act, 1998). According to Mandelstam’s (2006) discussion on the law and assistive technology for dementia, this right could be interpreted either way since technologies can be used as part of a routine of ‘close control’ or enable a ‘loosening of close control’. In terms of the latter, ‘safer walking technology’ seems ethically preferable to baffle locks, chemical restraint etc. But this ethical conclusion could only be defended, if a clear risk-benefit analysis can be demonstrated for all other options (Principle 1, Scottish Mental Welfare Commission, 2005). Accordingly, any decision to allow ‘safer walking technology’ must be accompanied by ‘clear protocols and guidelines’ that demonstrate ethical practice in user and multiple stakeholder consultation (Principles 3-5, ibid). Marshall (2000:41) argues that completing and signing an ethical protocol
foregrounds ethical issues for all stakeholders and provides an audit trail of accountability. If the final decision is to commission some form of Telecare, it is then possible to conceive of 'safer walking' technology as a kind of spectrum with 'tagging' at one end and more user-interactive technologies on the other.

The opponents of 'tagging' see it as a restraining technology associated with locking up criminals or protecting children and should have no place in the support of autonomous adults (O Neill, 2003). Furthermore, it can be argued that tagging technologies can create laxity in human surveillance. Yet, in advanced cases of dementia, electronic containment by ‘tagging’ and outdoor tracking’ through Global Positioning by Satellite (GPS) may be ethically defensible since,

‘The increased risks associated with wandering include a greater risk of falls... the risk of damage to the home, the risk of becoming lost and the risk of injury or death' (Plastow, 2006:525).

GPS products such as the 'wander guardian' regularly scan the location of the user (e.g. at 30 second intervals) by linking to a wearable electronic tag. GPS locator tags can be fobs worn on key rings or incorporated into pieces of jewellery such as bracelets, watches or pendants. Such personal customisation can make their use more personally acceptable and less a stigmatising marker of disability. This normalisation also makes users with dementia less visible to others, especially those with predatory intent.

But 'safer walking' technology need not necessarily mean 'tagging' which is in any case a very loaded term. There are also 'door exit alarms' which contact a Telecare Response Centre or a local carer if the end-user has moved outside a demarcated safety zone. However, their effectiveness and ethical acceptability crucially depends on the rapid response of committed human agents (Alzheimer's Society, 2007b).

The DHC professional is also reminded that an ethical case can be made for temporary 'safer walking' technology for assessment and care planning purposes. This can provide objective data for verifying or challenging other people's accounts about any putatively problematic ‘wandering’ (Advanced Telecare Users' Group, 2008).

The DHC professional may agree that for milder forms of dementia, a more preferable ethical case could be made for ‘tracking’ technologies, if the user with dementia can use a mobile phone linked to the GPS locator system. Given adequate cognitive capacity, a mobile phone or similar portable device, allows the user telephone contact and hence is more empowering. It is notable that the use
of mobile phones is growing among older people in any case (Dunk & Doughty, 2006), so that future cohorts will be more comfortable with their use.

Finally, if some form of 'safer walking' technology' must be used, a rapid response to any event is essential. Even if a 'wandering' case is alerted to Telecare services, the speed and quality of their response may not guarantee a safe recovery. It is therefore not surprising that concerns have recently been raised by the Alzheimer's Society on the adequacy of Telecare 'Call Centre' responses to 'wandering' (Alzheimer's Society, 2007b). However, it is understood by the author that the quality of Telecare services for cases of 'wandering' are currently under serious review. For example, discussions are taking place at Hanover Telecare about securely storing photographs of missing people and other identifying details to pass to police and emergency services. There may also be a case for developing standardised UK Telecare databases along the lines of a national database such as 'Safely Home' (Alzheimer's Society Canada, 2009), a police managed database of people at risk from 'wandering'. This would contain identification details such as a picture, details of clothes and other salient characteristics of the temporarily missing person, subject to valid consent from the person or any advocates.

4.2.7 Balancing Enablement of people with dementia with their need for care

In seeking to illuminate Question 2, this section has looked at the tensions between enablement and containment in discussing Telecare services for dementia home support, culminating in the ethical exploration of 'wandering' technologies. In any home care package, the DHC professional therefore has to try to maximise the opportunities for enablement and minimise forms of containment for the home service user with dementia. However, the ethical problem is that focusing on independence and empowerment may be over individualistic, in line with criticisms of some models of 'person centred care' (Adams, 2008a). Also ways of promoting individual empowerment, though desirable as an ethical goal, may themselves be oppressive for vulnerable service users who are highly dependent. Furthermore, dementia is often experienced in relational contexts. People with dementia can present communication and behavioural challenges which need committed input from trusted others, whether we term it 'assistance, help or care' (Shakespeare, 2000). The DHC professional could therefore be designing and commissioning a home care package which may need to be as relationship-focused and family system-focused as individually-focused (Forbat, 2008). In the interests of ethical practice, the DHC professional has therefore to explore how Telecare services might impact on the service user's experiences of informal and formal care and on such care.
providers themselves. This consideration leads to Question 3 of this Thesis.

4.3 Question 3: How are Telecare Services Impacting on the Relationship between the Person with Dementia and Significant Others, Particularly Informal and Formal Carers?

This Question focuses on the possible relational impacts of Telecare services in dementia home support. This question is critically significant because the qualitative foresight studies on Telecare highlight such dichotomies as ‘human’ versus ‘technical care’. For example, in the Sivertsen et al. (2006) interview study, the researchers’ overall observation was that

'Participants feared that the use of ICT would propel development towards a dehumanized care of older people, where the focus was on efficiency and remote control'. On the other hand, they described ICT applications to have the potential to promote well-being and to assist an individual older person with some of their needs’ (esp. cit., 221).

An outline of issues to be addressed by Question 3 is presented in the following table:

<table>
<thead>
<tr>
<th>Clinical Opportunities</th>
<th>Clinical Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Users are a highly regarded resource in care provision</td>
<td>Possible reduction in cost and quality of care</td>
</tr>
<tr>
<td>Social and technological support</td>
<td>Further access of ‘unnecessary’ care to people with dementia</td>
</tr>
<tr>
<td>Telecare can re-engage care teams positively</td>
<td>If users are considered barriers to technology use by professionals</td>
</tr>
<tr>
<td>Supportive Technology can assist users in adopting new tools</td>
<td>Telecare may be used as part of the ‘practise of absence’ of the former full-time carer</td>
</tr>
<tr>
<td>Mobile telecare uses can be key useful for service planning</td>
<td>Caregiver’s illness as 'caregiver’s burden' is negatively viewed</td>
</tr>
</tbody>
</table>

4.3.1 Informal Carers and Telecare

In exploring the possible outcomes of Telecare services for informal carers, a key consideration is the background tension between those who maintain that ‘every’ needs are best met through improved services for service users and those who support the carers’ campaign for services in their own right (Lloyd, 2000 cited in Parry & Clarke, 2001: 124).

Overall, although there is general recognition of informal carers as key issues, carers and supportees for various technologies, informal carers’ own evaluations of respective telecare services
4.3 QUESTION 3: HOW ARE TELECARE SERVICES IMPACTING ON THE RELATIONSHIP BETWEEN THE PERSON WITH DEMENTIA AND SIGNIFICANT OTHERS, PARTICULARLY INFORMAL AND FORMAL CARERS?

This Question focuses on the possible relational impacts of Telecare services in dementia home support. This question is ethically significant because the qualitative foresight studies on Telecare highlight such dichotomies as ‘humane’ versus ‘inhumane care’. For example in the Savenstedt et al. (2006) interview study, the researchers' overall observation was that,

‘Participants feared that the use of ICT would propel development towards a dehumanized care of older people where the focus was on efficiency and remote control. On the other hand, they deemed ICT applications to have the potential to promote well –being and to assist an individual older person with some of their needs’ (op. cit., 22).

An outline of issues to be addressed by Question 3 is presented in the following table:

Figure 16: An outline of ethical issues relating to Telecare services and informal/formal care

<table>
<thead>
<tr>
<th>ETHICAL OPPORTUNITIES</th>
<th>ETHICAL CHALLENGES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers are a highly regarded resource in user centred design. E.g. ENABLE.</td>
<td>Virtual care may replace face to face care</td>
</tr>
<tr>
<td>Telecare can re-deploy carers more productively</td>
<td>Possible rationalisation and cost pressures for more ‘virtual care’</td>
</tr>
<tr>
<td>Supportive Technology may ease burden on informal carers. Lifestyle monitoring tools can be very useful for care planning. Telecare may contribute data for ‘Carers Assessments’</td>
<td>Further risks of ‘disembodied’ care for people with dementia</td>
</tr>
<tr>
<td>If carers are co-resident, home technologies can be problematic.</td>
<td>Telecare may become part of the ‘circuit of surveillance’ of the welfare state such as for checking informal carer’s eligibility to Carers Allowance.</td>
</tr>
</tbody>
</table>

4.3.1 Informal Carers and Telecare

In exploring the possible outcomes of Telecare services for informal carers, a key consideration is the background tension between those who maintain that, ‘carers’ needs are best met through improved services for service users ...and those who support the carers’ campaign for services in their own right’ (Lloyd, 2000 cited in Parker & Clarke (2002: 354)).

Overall, although there is general recognition of informal carers as key users, co-users and supporters for various technologies, informal carers’ own evaluations of assistive technological
packages are not well understood. This lack of understanding seems rather surprising given the official endorsements of 'supportive' technologies for carers in the English National Strategy for Carers (Dept.of Health, 1999). Likewise, the Audit Commission (2004a:19) argues:

'AT [Assistive Technology] can amplify the efforts of carers, thereby helping to bridge the demographic gap between the growing needs for personal care and the shortage of carers available to provide it. Telecare technology in particular can relieve carers of some simple, tedious and often intrusive Tasks [My emphasis].'

As an aid to speculation about the impact of Telecare services on carers, the DHC professional’s attention is drawn to the following table. This is based on Twigg & Atkin's (1994: 11-15) four 'models' of how services 'position' informal carers: carers as 'resources, as co-workers, as co-clients or as superseded carers'.

Figure 17: Possible Service Outcomes of Telecare Services for Informal Carers

<table>
<thead>
<tr>
<th>Telecare as a Service From Carers?</th>
<th>Telecare as a Service With Carers?</th>
<th>Telecare as a Service For Carers?</th>
<th>Telecare as a Service Without Carers?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer as resource</td>
<td>Carer as co-worker</td>
<td>Carer as co-client</td>
<td>Superseded Carer</td>
</tr>
<tr>
<td>Danger of exploitation of informal carers putting them at risk of unsustainable carer burden.</td>
<td>Partnership welcomed but too much empowerment can be experienced as oppressive by carers if it is too morally burdensome.</td>
<td>Service providers need to be sensitive to multidimensional aspects and trajectories of informal caring.</td>
<td>This model should enable the choice of not to care. This seems to concur with a number of disability rights perspectives.</td>
</tr>
<tr>
<td>Telecare may be seen as exploitative of informal 'care on the cheap'. This is reminiscent of previous community care critiques of female family care.</td>
<td></td>
<td></td>
<td>There are superseded carer possibilities presented by Smart Home (e.g. Gloucester Smart House) developments for dementia.</td>
</tr>
</tbody>
</table>

A strong prime facie case can be made for some positive outcomes for informal carers from Telecare services, albeit speculative. At one extreme is the possibility of more effective virtual care at a distance, through 'supervisory and monitoring care' (Nolan et al., 1995; 1996). For example, some positive impacts on informal carers are noted in the West Lothian 'Housing with Care' study:

'From the carers' point of view, many of the burdens of care had been relieved, and they no longer spoke of themselves as overwhelmed by caring tasks.. This also had the added benefit of more family inclusion for all concerned' (Bowes & McColgan, 2003b: 44).

Similarly, Price (2007a, b) makes a strong case for the benefits of home monitoring systems like 'Just Checking' for informal carers. She argues that such systems can reduce the need for brief
'check visits' which seem of little use to the person with dementia anyway and can often be anxiety and guilt-ridden. Therefore she claims that technologically informed carers' visits, though less frequent, can be longer, better quality and more mutually beneficial.

Yet, the jury is still out on the 'benefit-burden' balance from Telecare services to informal carers, necessitating further empirical work. From the perspective of some of the literature, Telecare packages can even impose additional burdens on informal carers (Barlow et al., 2003). This can be true of home care technologies in general since their operation and maintenance can demand a high degree of input from humans (Lehoux et al., 2004). The DHC professional should note that a high reliance on informal carers has already been noticeable in the ENABLE studies of assistive technologies for dementia (e.g. Bjorneby et al., 2004) and this kind of dependence can easily be exploited by service providers. Furthermore, the economic benefits of technologically enabled services can mask their 'care on the cheap' consequences, reminiscent of feminist critiques of gendered care-giving in the 1980s. Indeed, the effectiveness of Telecare's 'social response' may be an over reliance on informal carers or emergency key holders.

On a more positive note, where informal carers freely choose their continuing role, as 'co-workers' or 'co-clients' of services, Telecare services allow opportunities for up-skilling towards the role of the 'expert carer'. Yet, the 'expert carer' can become the over responsible 'solo carer' (Nolan et al., 1996), putting the care-recipient and possibly the carer herself or himself at risk. The DHC professional should also bear in mind general ethical concerns about the 'professionalisation' of 'lay carers' without adequate formal support (Pickard et al., 2003).

Overall therefore, we seem to need much more empirical studies on how Telecare services are impacting on informal care. If positive benefits of Telecare to services users with dementia and to carers themselves are seen to accrue, we may see more campaigning for carer-friendly Telecare services in the future. Already it is noteworthy how informal carers’ advocacy groups are taking positive views of the potential of Telecare and assistive technologies in general to support them. In this regard, the 'Care 21 Report' on the future of informal care in Scotland is particularly noteworthy:

'Telecare may prove to be vital to supporting the contribution that unpaid carers make. Specific consideration should be given to the role of 'telecare' in the development of policy and services for unpaid carers. Therefore carers and their representative organisations should be consulted about the scope for the application of telecare' (Office of Public Management, 2005: 30).
4.3.1.1 Additional ethical issues for shared home users.

There is considerable scope for exploring some of the unintended outcomes of assistive technology packages, especially for co-resident carers. As Hyysalo (2004: 214) has noted:

'... new technology shifts burdens and responsibilities among its utilizers: while some people and some projects benefit, others may be just burdened and potential bottlenecks may be introduced into these implicated practices'.

Any home delivered technological service for someone with dementia, might undermine the welfare of other home users. Arras and Dubler (1995) claim that the presence of some home healthcare equipment can alter the symbolism of familiar home spaces, making the home seem over 'clinicalised' to co-occupants. It is therefore possible that impositions of home technologies could be challenged under Article 8 of the Human Rights Act (1998) which upholds respect for private or family life.

Ideally, lifestyle and medical monitoring technologies ought to be calibrated to take the lifestyle patterns of other home occupants, visitors and even pets into account - it is quite common for cats to step on the 'integral button' of a home Telecare base unit, for example! An 'intelligent toilet' (Brownsell & Bradley, 2003) for monitoring urine glucose levels for someone with diabetes would have to be designed to distinguish other users. For lifestyle monitoring technologies, the problems of discriminating the monitored subject from others continue to present technological challenges though there are encouraging developments in 'Radio Frequency Identification' technologies (Ni' Scannail et al., 2006). The development of such technologies could of course create additional surveillance circuits in the home (Heaton, 1999), where informal carers themselves could be monitored for their ongoing eligibility for Carers' Allowance and other carer support services.

There still seems much scope for developing ethically acceptable solutions to the inter-personal boundary problems between people with dementia and their co-resident carers and the DHC professional might need to be involved in such negotiation.

4.3.2 Telecare and Formal Carers

There seems widespread ethical consensus that Telecare can complement other forms of support but should never substitute for them. Accordingly, there are policy expectations that Telecare can complement traditional care, both informal and formal. For example,
'It [Telecare] can give carers more personal freedom and more time to concentrate on the human aspects of care and support and will make a contribution to meeting potential shortfalls in the workplace' (Dept of Health, 2005 cited in Hanover Telecare (2007)).

Yet, it is the latter question of meeting 'potential shortfalls in the workplace' that creates ethical disquiet, especially around vulnerable service user groups. The claims for anticipated careforce shortfalls could be used as a cover to legitimate the reduction of formal services for some home users and Telecare services may be deployed for this purpose.

It is hard to compare the cost of Telecare services to other home care services due to limited data on Telecare economics so far. However, one cost comparison estimate has been provided by Doughty (2007:24), taking capital and running costs into account:

'It The weekly cost of providing a high level (assessed) Telecare service is likely to be in excess of £15 and comparable to the cost to the Council of providing one hour of home care'.

This means that if a preventative Telecare package could be used to reduce an hour of weekly home care, then the service commissioner/provider would break even. With any additional savings in home care by Telecare replacement, a strong economic benefit is demonstrable. Accordingly, it is already noticeable how in some of the published performance statistics to date, a reduction in home-based services is listed as a ‘benefit’ of Telecare. For example, in a recent progress report on Telecare development in Scotland, the authors observe:

‘By September 2007, the Telecare Development Programme funding was responsible for a minimum of 1, 250 nights of sleepover care and 107, 000 home check visits saved [My Emphasis]’ (Joint Improvement Team, 2008a:2).

The DHC professional is also cautioned that parallel claims on 'benefits' to community nursing services from professional ‘virtual visiting, especially in remote areas, may require continual ethical vigilance:

'Studies of community nursing activity have found that up to 46 per cent of visits could be replaced with remote monitoring ... Virtual visiting is particularly powerful when used to monitor the safety of dementia sufferers who live alone' (Audit Commission, 2004a).

Even for the conscientious DHC professional or carer who is critically aware of strategic and systemic biases towards rationalisation, the promotion of ‘Virtual care’ could be used as a form of convenient ‘distancing strategy’ from the perceived distress of dementia. This is because in some circumstances, Telecare services will allow formal carers and professionals some discretion in the choice of face – to -face visiting or remote safety monitoring. For example, in the West Lothian
‘Housing with Care’ literature support staff describes their changing roles as a result of Telecare technologies:

‘If something happens to a tenant, then there is the Lifeline [Link to a call centre] that contacts staff. We don’t have to go round everybody [asking] ‘are you OK?’ or ‘is something happening?’ We know what is needed when it is needed. Makes us confident that if anything does happen, we will know’ (Bowes & McCollan, 2003).

But such technologically-enabled choices have ethical ramifications which need to be carefully interrogated, especially for someone with complex needs. Telecare could be used as a distancing strategy or personal ‘electronic shield’ by some carers or health visitors from the understandable distress sometimes generated by dementia (Goldsmith, 1996). As a result, the Savenstedt et al. (2006) study recommends forms of accountability whenever professionals or staff chose remote monitoring over personal contact, as an ethical safeguard in ICT-enabled home care.

From an actuarial perspective, the ‘virtual visiting’ possibilities of Telecare might also reduce the riskiness of private homes as workplaces for otherwise home visiting care personnel. Therefore, in addition to Telecare for the service user, some form of safety monitoring of Telecare responders, home care workers and other visiting professionals might also be developed. This is in recognition that home care can be a hazardous activity (Taylor, 2006; Taylor & Donnelly, 2006) so that under the Health and Safety at Work Act (1974), an assessor has a duty of risk assessment for any employees such as a Telecare responder service. But the resultant ethical danger is that the promotion of home care services incorporating Telecare could be used more as part of a risk reduction strategy for home care workers rather than the outcome of careful ‘person centred care’ planning for the service user.

This exploration of Telecare’s possible impact on carers, leads to deeper ethical questions in the literature about the ethical balance between ‘high tech’ and ‘high touch’ (Naisbitt, 2001) for both formal and informal input in dementia home care.
4.3.3 Common ethical issues for informal and formal care: ‘High tech’ versus ‘high touch’

Isolation and loneliness can be key problems of old age generally. These issues may be further compounded by the growth in single person households and more ‘individualized living’ (Beck, 2002 in Blythe et al., 2005). Most significantly, the question of the need for human contact cannot be evaded easily because it is prioritized by many older people themselves:

‘Although safety may be the main concern of some relatives and authorities... older people themselves worry about other things such as loneliness, privacy and freedom to live as they wish... a better understanding of our need for human contact and how different communication technologies might best support that need could considerably improve the quality of life of many isolated older people’ (Blythe et al., 2005, 687).

The risk of isolation seems especially critical in the care of people with dementia, who may need stable trustworthy relationships to nurture their ‘personhood’ as,

‘Dementia ... makes a person exceptionally dependent on others: not only in the physical sense, but in a psychological sense as well’ (Kitwood, 1997).

It is therefore no surprise that ethical tensions between ‘high tech’ and ‘high touch’ are a very
salient concern in some of the foresight literature on Telecare surveyed for this study:

'Good care for older people was described as being linked to genuine relationships and social interaction. ...Older people with dementia need to have staff members around them in order to prevent chaos and to be able to calm down the situation when they are anxious and restless' (Savenstedt et al., 2006:20).

These ethical views link to more fundamental arguments in the moral philosophical literature that 'Telepresence' and 'disembodied' care are morally inferior to face to face care (e.g. Bauer, 2004 in Barlow, 2006). This can be coupled with concerns in the general literature on the construction of 'future patients' through 'Telehealthcare'. Here remote health monitoring is feared to be 'fragmenting' the 'life world' of the patient, in ways that are 'detached from ways of knowing and understanding the patient relationally as a human and social being' (Finch et al., 2008: 91). Such ethical caveats may be particularly relevant for a high relationally-dependent condition such as dementia.

Although policy sources will continue to assert that Assistive Technology in general has to complement human caring and not substitute for it, there are still suspicions that Telecare services may represent the gradual substitution of human caring by stealth. The DHC professional ought to be critically aware that Telecare data could be used as a tool to reduce home care services for older people if it could be demonstrated that Telecare is improving self-help or reducing costs (Doughty, 2008b). Yet, the DHC professional should be also aware that concerns about the 'substitutability' of human by technological support may be sometimes misplaced, because of the observations presented in the next sub-section.

4.3.4 Ethical and Legal limitations on 'high-tech' developments relevant to dementia home care.

Despite technological sophistication, some aspects of personal wellbeing would only appear assessable and addressable by home care visits – keeping warm, adequate nutrition, hydration, home cleanliness and personal hygiene. The regular monitoring of such wellbeing by home care staff seems ethically fundamental for some forms of dementia. For example, common conditions like 'dressing apraxia' in dementia could only be supported by a carer (Anderson, 2008), unless advanced robotics are developed to provide suitably-sequenced tactile as well as visual cues! Likewise, Adams (2008b: 35-36) argues that 'reading the body' is an essential component of dementia care nursing where 'many people with dementia often find if difficult to communicate through talk and can only make themselves understood through their body'. In any case, the Botsis
& Hartvigsen (2008) review, shows the general inappropriateness of most current 'telehealthcare' programmes for people with dementia, even if demonstrably successful for other health user groups.

As well as their limitations in ongoing bodily care, Telecare services can only provide part of the solution to the common problem of falls. In practice, a user can wear a fall detector which is Telecare-enabled but this is increasingly seen to be only part of a comprehensive fall management service. As a more ethically ideal responsive system, the Falkirk ‘Falls Management Project’ offers complementary services to Telecare with specialist clinics offering multi-disciplinary assessment, equipment, advice and therapy services (Joint Improvement Team, 2008a).

The issue of medication non-compliance is also ethically significant, where as many as 50% of older people on medication may not be compliant with their prescribed regimes (National Institute of Clinical Excellence/Social Care Institute of Clinical Excellence, 2006). The problem of medication non-compliance by a home based person with dementia may be a significant trigger for premature institutionalisation (Smith et al., 2007). This problem is compounded in the multiple drug requirements for co-morbidities in older age, with the cognitive disabilities of dementia further hindering medication concordance. In most cases, home care workers and sheltered housing wardens are only allowed to prompt for medication intake (Alzheimer Scotland, 2008). This presents significant ethical challenges for safe and sustainable home care. As one Care Manager in Meeting Our Needs notes,

"Medication is our biggest problem, carers are not allowed to administer, only prompt and this sometimes leaves people only with the option of long term care" (Alzheimer Scotland, 2008: 20).

Technological attempts to address this challenge are still evolving. Linked to Telecare, an automatic pill dispenser can remind a user to take his/her medication. If this is not done, a call is sent to the Telecare Response Centre where an operator prompts the user to open the pill box for the dosage:

'The Norwich STILL project group is ... piloting the use of a 'prompting service' for a small number of people provided by the Telecare operators at the Response Centre... The operators ring through prescribed reminders such as ... medication takes' (Faife, 2006:37).

Such projects require the agreement and cooperation of pharmacists to fill the pill dispenser in the first place, which is understood to be presenting challenges in practice (Advanced Telecare Users' Group, 2008). But such phone prompting services do not ensure medication compliance. For some cognitively impaired people, a regular supervisory arrangement would also have to be put in place so that self-administration of medication can be witnessed. Alternatively, there may be a growing
ethical case for some form of time-limited video monitoring for medication intake. Some researchers are demonstrating medication compliance-success in small scale trials of interactive video for people with mild dementia living alone (Smith et al., 2007). However, far more ethical assessment needs to be done for such Telecare applications and, if they receive ethical clearance, their effective implementation would have huge resource implications for Telecare services.

Another ethical question is how Telecare evidence for successful self-care might impact on any formal home care services. It is suspected that if Telecare data analysis suggests that a person is managing more than conventional assessment and observation suggests, this could mean the withdrawal or reduction of home care services. On the other hand, it is argued that Telecare allows better tailored and more flexible services for the home-based user with dementia since,

"Technology does ... create opportunities for using care more creatively. By using technology to reduce visits for the purposes of supervising medication or to check on a service user's well-being it would be possible to re-configure care so fewer visits occur but where those visits do occur they are of longer duration" (Woolham et al., 2007:18).

For example in Price's (2007b) study of 'Just Checking', a home lifestyle monitoring system, one service user was shown to be self-nourishing properly but neglecting personal hygiene so services were customised accordingly:

"Two [care managers] made changes to the care package as a result of the information, one reduced the number of daily home care visits from two to one, and changed the tasks from meal preparation (which was not needed) to encourage the services user to shower and change her clothes... [In another case] some further support for the [informal] carer was organised" (Price, 2007b, 14).

Neither, can we naively assume that ICT support is always morally inferior to human contact. Excessive or unsuitable home care services can be intrusive and destabilising for service users with dementia, as well as other household members. Some Telecare services therefore have an ‘I’m OK’ button connected to the Telecare Response Centre which the service user presses every morning if not requiring a 'check visit'. Some Telecare services can also be configured for scheduled telephone contact, for reminders of appointments and medication prompts (Faife, 2006). Carers UK (2008) also suggest that informal carers could pay Telecare services to book reassurance calls and reminder calls in advance for their carees, when carers themselves are absent, away or ill and unable to care. Such trends are analogous to the growing evidence that proactive support by telephone from professionals, can improve clinical outcomes for some populations with chronic illness:

"Trials and observation studies found that regular telephone calls from nurses reduced or delayed hospital admissions and costs in people with heart disease... asthma... and the elderly' (Barlow et al., 2007:178).
A person may prefer such forms of Telecare in the interests of personal and family privacy. But though proactive Telecare seems ethically desirable for some independent people with dementia, not all Telecare services will have the capacity, staffing or funding to provide such a service. Far more research is therefore needed on the community care impacts of such proactive innovations and if found beneficial, a case made for more resources.

Finally, there seem to be legal brakes in some parts of the UK on any Telecare development which could implement any ill-considered substitution of human care by technology. For example in England, if a person is found to have an ‘...eligible need, the local authority has an absolute duty to meet that need one way or another, irrespective of resources and without undue delay’ (Mandelstam, 2006: 70). The statutory duty on English local authorities to meet ‘eligible need’ of course depends on the comprehensiveness and depth of the assessment tool used and the permissible definition of ‘eligible need’ under the Fair Access to Care Services (FACS) criteria. If ‘eligible need’ includes socio-emotional needs, then the Local Authority or Care Partnership is duty bound to arrange matching services. Accordingly, in a review of the law and assistive Technology in England, Mandelstam (2006) cites several cases where the courts held that local authorities must take account of a person’s psychological and emotional needs, cultural needs, and choices for human contact in preference to any ‘virtual’ substitutes. So a key ethical question here is not so much about the content of Telecare services, but whether they can be deemed adequate to meet eligible need for services.

Because of the previously discussed ethical and legal limits to ‘high-tech’ forms of home support for people with dementia, some anxieties about Telecare services as a cheap and convenient substitute for care may be overstated. However, these ethical issues will become clearer as Telecare services develop and more empirical evaluations are carried out. In the meantime, some ethical questions about the balancing of ‘high-tech’ with ‘high-touch’ are beginning to be illuminated by the growth of ‘smart house’ models for people with dementia. The concept and implementation of smart housing models for people with dementia and their relevance for Telecare services, will therefore now be explored.

4.3.5 Example 5: Smart homes for people with dementia.

The ethical dynamic between ‘high tech’ and ‘high touch’ for people with dementia, is well illustrated in the concept of the Smart House. In the field of dementia support, a strong case for the effectiveness of smart house technology was first established by ‘Project BESTA’ in Norway
In general, a Smart House is an internally networked system of electronic assistive technologies to support safe independent living. Technically, the Smart House is configured around an electronic ‘hub’ to coordinate remote control devices and automatic systems where,

‘Hand held devices can perform a range of functions such as opening doors and windows... whilst remote sensors can detect gas leaks, raise the alert to scalding water and monitor state of health’ (Franklin, 2006:169).

For a vulnerable occupant, the Smart House acts as a form of ‘electronic homoeostasis’ where ‘... sensors... produce a holistic care environment producing a range of feedback on the person being monitored’ (Dewsbury et al., 2004:5). From its various feedback circuits, the Smart House can generate a hierarchy of responses depending on how it assesses the health and safety status of the occupant. When the smart house ‘decides’ the user needs help, sets of ‘alarm, alert and assist’ (Kinder, 2003) mechanisms kick in. These are usually sequenced as follows:

1. Issue a message to the end user e.g. ‘The gas cooker is unlit’
2. Automatically turn off the threat e.g. The gas supply to a particular appliance or to the whole house, is isolated
3. Summon outside help if necessary according to a pre-determined ‘escalation sequence’ e.g. TRANSCO for gas alerts, then any carers and formal responders and then CORGI registered engineer for reconnecting supply.

Although in theory Smart Houses can exist as internal networks they are more likely to be electronically connected within a ‘Housing with Care’ complex or externally to a Telecare Response Centre. Such connectivity seems imperative for people with dementia to provide back up support in any electronically detected home crisis or emergency.

The DHC professional should note that derivative ‘smart technologies’ can be installed in the homes of people with dementia, without having a full Smart House system. Such sub-systems exist for mitigating commonly perceived risks, such as those summarised by the National Audit Office (England):
In the community, people with dementia face risks. For example, they may forget to switch off a cooker or turn off taps, risking fire or flood; they risk injury from wandering or falls and some may hurt themselves or be violent to others. Self-neglect is another risk – forgetting to take medication, to wash, eat or drink' (NAO, 2007:32).

4.3.5.1 Designing the Gloucester Smart House as a dementia-friendly environment

Overall, the Gloucester vision was of a ‘dementia friendly’ home environment in line with best practice in older design (Goodacre et al., 2007; Judd et al., 1998). Every attempt was made to involve people at various stages of dementia in accordance with the principles of user-centred design. The designers had to take account of levels of cognitive impairment as well as other sensory disabilities, physical impairments or chronic conditions of a typical home occupant. But this was only possible with a small number of potential users as failure of prototypes caused distress and rejection of the proposed technologies. There was more end-user involvement at a later design stage, when the more mature devices were tested with the users with dementia themselves. Because of such barriers to inclusion of people with dementia, their informal carers had to be fully involved in the design concept from the earliest stages:

'It was argued that if carers had the greatest intimate understanding of the problems involved in supporting someone with dementia, and if they had found effective strategies, then these strategies ought to form a good starting point for any design work' (Orpwood et al., 2005:159).

The evolving vision was one of ‘emulating care’ so that the ‘technology needed to react in a very similar manner to a lived-in carer’ (Orpwood et al., 2005:159), due to the reality of intermittent carer absence. The ‘carer strategies’ used in carer-defined problem situations were modelled and electronically implemented. The process of such ‘Carer emulation’ is illustrated in the following diagram:
Figure 19: Designing the sequence of Carer emulation in the Gloucester Smart House.


Three short 'risk scenarios' in the Gloucester model illustrate some of this 'carer emulation' for people with dementia:

**Safe Bathing**

The parallel safety sequences of running a bath for carer and smart house are compared in the following table:
Figure 20: Translating carer interventions into computerized algorithms for water safety.

<table>
<thead>
<tr>
<th>Carer philosophy</th>
<th>Smart design philosophy</th>
</tr>
</thead>
<tbody>
<tr>
<td>'The carers were conscious about empowering the person rather than taking control away from them. So they would tend to encourage the person with dementia to resolve the problem for themselves rather than doing things for them' (Orpwood et al., 2005:160).</td>
<td>'... A general principle for all smart house work is that the house doesn't take over control from the user, but rather empowers them (160)'.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer Intervention Sequence</th>
<th>Computer Intervention Sequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>First, provide a reminder: 'Don't forget you've left the bath running'</td>
<td>First, Pre-recorded reminder to user via wall mounted speaker: 'Don't forget you've left the bath running'</td>
</tr>
<tr>
<td>Second, if no response from user, carer turns off tap...</td>
<td>Second, if no response from user, Smart house turns off tap without locking it.</td>
</tr>
<tr>
<td>Third, let the user know: 'Your bath is ready, I've turned the water off'.</td>
<td>Third, Speaker message to user: ‘Your bath is ready, I've turned the water off’</td>
</tr>
<tr>
<td>Fourth, allow the user to add more water if needed, thereby allowing optimum control.</td>
<td>Fourth, user is still able to add more water, subject to a safety threshold.</td>
</tr>
</tbody>
</table>

Based on Orpwood et al. (2005:160).

Safe Cooking

An analogous safety escalation sequence is activated to monitor safe cooking. In the first instance, direct feedback is provided to the person via visual signals and voice prompts (e.g. ‘you have left the cooker on’). If the user does not turn the cooker off, shut-off devices are activated. Furthermore, a Telecare data signal is received by a Telecare Operator who may action an emergency response.

Night Safety

Another example with ethical ramifications is for someone with dementia who is prone to night ‘wandering’. A pressure sensor under the user’s mattress signals the room lights to fade up when a resident gets out of bed. If he/she opens an exit door, a pre-recorded message prompts the user to return to bed. If the home user is unable to respond to the message then the smart console sends an ‘alert’ to a nominated key holder and/or Telecare Response Centre, depending on a pre-negotiated arrangement. In this way a preference hierarchy of safety responses is enacted. How the smart
house responds as a care emulator is outlined in the following diagram:

Figure 21: Night Safety System for user with dementia.

<table>
<thead>
<tr>
<th>User behaviour</th>
<th>House reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get out of bed at night</td>
<td>Light fade on</td>
</tr>
<tr>
<td>PIR</td>
<td>“I’ve turned the toilet light on for you dad”</td>
</tr>
<tr>
<td>PIR</td>
<td>No action</td>
</tr>
<tr>
<td>Wander for &gt;10 minutes</td>
<td>PIR</td>
</tr>
<tr>
<td>PIR</td>
<td>“You should go back to bed now dad”</td>
</tr>
<tr>
<td>Get back into bed</td>
<td>PIR</td>
</tr>
<tr>
<td>PIR</td>
<td>Light fades off after 3 mins</td>
</tr>
<tr>
<td>Still wandering after 15 mins</td>
<td>PIR</td>
</tr>
<tr>
<td>PIR</td>
<td>Care staff alerted</td>
</tr>
</tbody>
</table>

4.3.5.2 Ethical issues in dementia support raised by the Gloucester Smart House and similar models

- How the user interacts with the smart house, may be a useful assessment tool in itself. Serna et al. (2007) claim that error patterns in carrying out activities of daily living may correlate with ‘stages’ of Alzheimer’s disease. Further validation work is required for such assessment tools but there is huge potential for accurate continuous assessment of the occupant, especially if capacities fluctuate or the dementia condition deteriorates.

- Automatically alerting the user as a first step to any critical event, seems ethically desirable as it promotes autonomy and control. It also respects privacy as domestic problems can be self-managed and not publicised unnecessarily. For instance, one application of the Gloucester Smart House is in the 'Hillside Care Flat', used for intermediate care after a hospital stay:

‘...The system is able to respond to many different situations within the flat, without having to contact care staff, often just using simple voice prompts. It ... gives residents a greater feeling of control as it doesn’t rely on people coming in from outside to resolve problems, with outside help only called in for real emergencies ’ (Dementia Voice, 2008).

This model obviously prioritises self-support as a first step. Similarly, in the Norwich Smart Home, the smoke detector can be linked to a vibrating pillow or a flashing strobe light for people with visual impairment before any outside help is alerted (Faife, 2006). Such smart home innovations laudably promote optimal autonomy.

- Optimising autonomy may be ethically desirable, but there are ethical concerns about the possible over use of voice prompting as a substitute for more regular human interaction for people with dementia. ‘Simulated presence technologies’ such as ‘memo minders’ which produce pre-recorded messages even from recognisable voices, may be psychologically harmful for some service users (Astell, 2006). Similar ethical concerns have been voiced by a formal carer in the ‘Opening Doors for Older People’ project in West Lothian:

‘... I am concerned about the devices like the water level detector in the bath, which may use a daughter’s voice to tell the mother to turn the water off. They may be hearing
voices anyway and then go looking for the person they have heard. It could cause a lot more anxiety than it would help’ (Bowes & McColgan, 2002:17-18)).

Electronic disembodied voices are clearly unsuitable for some people as they may be easily startled and distressed. More seriously, they could trigger hallucinations. But live Telecare messages from the Telecare Response Centre may seem equally objectionable. For this reason, and only after careful individual assessment, the service provider Hanover Telecare forbids operators from speaking to a small minority of services user with dementia. Instead, if a critical incident arises for such cases, the Telecare response protocols instruct direct keyholder, carer or Emergency Service contact.

- There are ethical tensions about the balance between autonomy and automation for any occupants of a Smart House. Macieuszek (2005) criticises some over-sensitive safety systems which can frustrate more able home occupants and any co-residents. Macieuszek (2005) therefore argues that ‘The technology should be so smart that it can adapt the degree of automation of a task to user competence, preferences, and the current situation’ (op.cit, 58). While his proposed ‘Adaptive automation’ is ethically desirable, this does not seem to be technologically possible at present. With growth in Artificial Intelligence research, this goal may be more realizable in the future.

- Although fail safe systems in a smart house will shut off water, gas supply or other environmental hazards, this seems ethically inadequate if a delay in restoring utilities puts the service user at risk. There are therefore practical issues to be negotiated about who reconnects ‘cut off systems’ after a crisis or emergency for vulnerable service users (Waddington & Downs, 2005).

- The scope of ‘automatic data processing’ of a Smart House where a human agent is not involved seems also limited under the UK’s Data Protection Act (1998) (Her Majesty's Stationery Office, 1998). For example, a robot or any piece of ‘smart house’ equipment could turn off the heating supply and fail to restore it in time, resulting in hypothermia to the occupant(s). A service user could then invoke his/her ‘Rights in relation to automated decision making’ and possibly pursue litigation since,
It is therefore to be welcomed that Smart House models are currently only being implemented in ‘Housing with Care’ contexts where rapid response teams are on local standby.

4.3.6 Smart Housing Applications and the link to Telecare services

Finally, the DHC professional will appreciate that the increasing electronic sophistication of smart house technologies holds the future promise of ‘automation-aided autonomy’ and less reliance on others. But the outcome could be forms of isolation which would seem ethically unacceptable for someone with dementia for whom human support and care may be vital lifelines. The main ethical lessons from the Smart House applications are that end-user autonomy can be optimised but overlays of reliable and rapid back up services are essential for various contingencies. Telecare Services seem ideally placed to coordinate such support and their ethical dimensions are the focus of Question 4 of this Thesis.
4.4 QUESTION 4: WHAT ARE THE ETHICAL IMPLICATIONS OF THE FORMAL SERVICE RE-CONFIGURATIONS THAT TELECARE IS INTRODUCING?

The hub of any Telecare service is the Call Centre or Telecare Response Centre. But there are concerns about the growth of the ‘Call Centre’ culture in health, social care and housing support services generally (Down, 2005; Percival & Hanson, 2006). As a result of anecdotal and newspaper accounts of public dissatisfaction in some cases, there is increasing demand for more ethical critique of such innovations. For example, the Alzheimer’s Society has questioned the capacity of Telecare Call Centres to respond to 'safer walking technology' alerts (Alzheimer's Society, 2007b).

However, for Telecare quality assurance purposes, there are strong inspection regimes in place such as the regular audits carried out by the Telecare Services Association (2006) to ensure that member services are code-compliant. But there is increasing concern that the performance indicators used in such inspections are insufficient and too mechanistic, not allowing for the complex needs that an increasing sub-population of Telecare users present (Advanced Telecare Users Group, 2008). For Scotland, this is all the more urgent if Telecare services will have the capacity to effectively support the 9000 dementia connections (out of 75,000) planned for 2010. It is therefore to be welcomed that the current Telecare Strategy for Scotland (Joint Improvement Team, 2008b) is investigating a possible role for the Care Commission in the inspection of Telecare services.

For a full ethical critique, there is a growing need for further research on the organisation of Telecare services and their integration with the wider formal service system. For the present, the attention of the DHC professional can nevertheless be drawn to some core ethical elements of Telecare services addressed in the literature to date:

- Telecare services and the social response;
- Telecare services, data governance and response protocols;
- Telecare services' interfacing with the wider formal care system.
4.4.1 The quality of the Telecare 'Social Response'

According to Wanless (2006:16),

'It is the infrastructure behind telecare that makes it viable, including the call centres and rapid reaction units'.

In order to be efficient, effective and ethically acceptable, Telecare Response Centres have to couple fast-accurate detection of any crisis event with a rapid social response. Incoming calls are prioritised according to pre-set urgency criteria. For example, the author understands that in a typical Telecare 'triage', fire emergencies are prioritised followed by Carbon monoxide/Gas emergencies, then floods, followed by personal trigger alerts. From the 'calls waiting queue' on his/her VDU, an engaged Telecare operator can also view the other calls stacking so can decide to switch to a higher priority call. This combination of automated prioritisation and Operator discretion ought to ensure that any urgent events are promptly responded to.

However, Telecare Call Centres often have other business some of which is not core Telecare. The DHC professional therefore has to assess what other services are provided along with Telecare by any providers he/she considers. This may have huge ethical implications for service users with dementia, because the Call Centre 'mix' may not just affect the speed of call handler response but the timing of any follow-on emergency response.

4.4.1.1 Telecare Service providers and other business.

Practice on combining core Telecare business with other business varies, as a recent Scottish review has shown (Joint Improvement Team, 2008c). In some Council providers, Telecare services are shared with other council services such as housing maintenance, environmental services and CCTV monitoring, so that call handlers will have a diverse skill set. Other services have separate centres for Telecare from other Council call handling business, as noted in the following Scottish observation:

'Generally, where the call handling service is for more services than Telecare/Community Alarms, all call handlers are expected to be able to handle all calls (for example in Scottish Borders, South Ayrshire). However, in some areas a separate team of call handlers for Telecare/Community Alarms is maintained (Falkirk, West Lothian) - although when there is heavy demand these staff can offer cover. Where there are separate teams, there is often (though not always) a direct link with response services. Such services can be perceived as a 'care' service, as distinct from a 'call centre' (Joint Improvement Team, 2008c:8).
In some of the Council Call Centres, Telecare business will operate out of the same centre as social work services. This joint working allows the merging of telecare and social care data, subject to confidentiality protocols. This leads to a better informed response to the increasing population of callers who are both Telecare and Social Work service users. Arguably, this symbiosis creates more of a care ethos for Telecare services than a merely home safety focus, which would seem to be critical for a lot of dementia clients.

But the quality of response crucially depends on whatever other business is concurrently in hand and Telecare services often have to manage a wide portfolio of customers to remain economically viable. For instance, the main non-profit organisations in Scotland such as Hanover Housing Association and Bield H.A provide Telecare services alongside out of hours repairs for some Councils. The challenge of how to manage core Telecare business alongside other business is likely to continue until the client base grows to make core Telecare services more sustainable. As an ethical imperative, it is hoped that the new Telecare Strategy for Scotland (Joint Improvement Team, 2008b) carefully considers this issue in order to support the extra dementia connections planned for 2010. However, the jury is still out on the ideal configuration on services for the growing population of more needy service users:

'Opinion is divided, both amongst managers and staff, over which is the preferred deployment. Some prefer the variety, and the 'multi-skilled' approach, where anyone can answer any call; others argue that specialist skills need to be maintained to deal sensitively and appropriately with alarms and calls from vulnerable, distressed people who may have significant confusion and/or dementia. No hard evidence to support either position has yet been identified' (Joint Improvement Team, 2008c: 10-11).

This author would incline to the latter view. This is because a prompt, reliable and more dedicated service seems essential if people with dementia are to be effectively supported in the community. The ideal service provision for dementia-friendly Telecare would therefore seem to be a local service or a remote specialist service:

'Mangers advise that many regular callers will develop a warm relationship with call handlers, and that this may be the only social contact that person has. Smaller centres appear to actively encourage this. This can lead to daily 'monitoring'/check up calls - where the call handler calls the service user for no other reason than to make contact and ensure that all is well. This is obviously a significant extension of an alarm service as it becomes an integral part of that person’s package of care and support... There may be a distinction to be made between call centres which see themselves, and have the capacity to be part of a care service, and those that are established as an emergency call centre [My emphasis]' (Joint Improvement Team, 2008c: 10-11).
There may also be a case for specialist Telecare referral services. For complex needs, proposals for forms of 'Teletriage' (Advanced Telecare Users Group, 2008) may be ethically ideal. This means that challenging presentations would be referred to specialist Telecare centres which are professionally staffed (e.g. London for learning disabilities, Manchester for speech impairment/stroke recovery, Stirling for dementia etc.). Such centres would mainly be staffed by healthcare professionals and screening Call handlers. Each professional would have a case-load with detailed knowledge of each Telecare service user from their Telecare 'Call History' and general social care plan. The promotion of working partnership with specialist telephone counselling services such as the Samaritans is also part of the current Telecare Strategy for Scotland (JIT, 2008b), subject to carefully negotiated data sharing protocols (Stead, 2008).

4.4.1.2 Coordinating a rapid social response

But fast-accurate detection of any hazardous events and customer focused interaction are necessary but not sufficient for a speedy response to any crisis or emergency. In this regard, Dunk & Doughty (2006) note that the efficacy of the prototypical Telecare projects in the 1990s were not so much limited by the quality of the networked technologies, as by their inability to coordinate a rapid response. Such a response is critical as a service user gets frailer, cognitively and/or physically. As a practical and ethical imperative, it therefore seems essential to try to anticipate the range of possible ‘alarm, alert, assist’ (Kinder, 2003) scenarios, matched to technological ‘solutions’ and explicit response commitments from different stakeholders.

However, orchestrating an effective ‘social response’ is proving to be challenging as current reflections on Telecare services demonstrate. Keyholder-dependability in particular is often experienced as problematic (Woolham, 2006a). Doughty (2008b) reports on a small scale random Telephone audit of keyholders in a Telecare service, finding that 31% did not answer, some had moved away, died, or changed their contact details. This means that for non-scheduled events, informal responders cannot always be relied upon and emergency services may have to be requested unnecessarily.

As a result, there seems a strong ethical case for more reliable formal response services as exist in Renfrewshire. This may be particularly the case for urbanised communities, in contrast to the kinds of ‘good neighbour’ Telecare arrangements that, in the view of the author as Telecare Operator, seem to operate very well in more dispersed rural communities.

Formal responder staff possesses a range of first aid and personal care skills such as lifting and
emergency toileting. They can also be trained in assistive/medical technological skills e.g. lifting equipment, catheter changing and operating defibrillators. Increasingly, 'Fire and Rescue Services' are partly funding responder services to carry out fire safety risk assessment and advise home occupants on fire protection (Advanced Telecare Users' Group, 2008). Ambulance services are also involved in responder training, because such training for non-injurious events such as falls can reduce demand on emergency ambulance services (Portsmouth City Council, 2007). Formal Telecare responder services are therefore evolving as a response to domestic events which are neither critical medical emergencies or do not coincide with any scheduled home care. In one sense, responders are a hybrid of low level paramedics and formal carers. Yet, on the other hand, formal responders are also factotums, often required for low-level home maintenance tasks beyond the ability of an older home user with dementia, such as changing light bulbs, restoring trip switches, turning off stop-cocks and restoring utility supplies.

As a Telecare Operator, the author has observed that there are often negotiation challenges between the remit of responders and that of scheduled home carers, so the evolution of the Telecare responder role has interesting implications for the division of labour in domiciliary care, healthcare and emergency services. As more evidence accumulates on how 'upstream' preventative innovations like Telecare might reduce demand for emergency services in particular, the skill set of formal responders and other Telecare staff has to be configured accordingly. It is therefore to be welcomed that the need for ongoing flexible training for Telecare staff and improved forms of information exchange with 999 services and NHS 24, is addressed in the National Telecare Strategy for Scotland (Joint Improvement Team, 2008b).

Planning a Telecare service also involves a duty of care to formal responders. Careful risk assessment is essential as responders themselves may be at risk in service users' homes, or may be assaulted if they are mistaken for an intruder. But the DHC professional will recognise that far more field data is needed to fully inform the ethics and legal implications of such developments.

4.4.2 Telecare services, data protection and 'response protocols'.

Telecare services raise fundamental ethical and legal issues for information governance. Data protection procedures are implemented within the UK legal framework, namely the Data Protection Act 1998 (DPA) (Her Majesty's Stationery Office, 1998) and the Freedom of Information Act 2000 (The Stationery Office, 2000). This legislative framework governs how health-related data is 'Held, Obtained, Recorded, Used and Shared' [HORUS] (Keen, 2007). The DPA confers a set of 8 rights
on 'data subjects' and obligations on 'Data Controllers' to protect the rights of any identifiable 'data subjects'. Special provision applies to 'sensitive personal data' and Telecare service providers such as Hanover Telecare have adapted these policies to their in-house records management and data governance procedures.

Telecare, like all ICT applications in the health care services, highlights issues of data confidentiality, due to the likelihood of data sharing between professionals, informal carers and others. To maximise empowerment of the service user with dementia, careful attention to their preferences about Telecare data processing and sharing must be prioritised, where valid consent can be obtained (Hughes & Baldwin, 2006). If not, this must be negotiated with any legally authorised attorney or guardian.

As an ethical priority, the DHC professional will note the attention given to the voice of users and potential users with dementia of Telecare services in the paper on ‘Safer Walking Technologies’ from the Alzheimer’s Society (2007b):

‘People with dementia are particularly concerned about the use of centres for monitoring tracking devices and the issue of confidentiality. For example, who would have access to personal information held centrally? Could a person with dementia be followed? Will call centres be obliged to carry out a Criminal Records Bureau check on employees’?

This observation is highly significant, especially the latter comment about the calibre of staff. This is because of the kinds of 'sensitive personal data' (Data Protection Act 1998, Principle 1, Schedule 1) that may be known by Telecare Operators, such as door security codes, personal medical details, sexual behaviour patterns, past criminal history and problem drinking (Stead, 2008). In addition, the Telecare service may have sensitive personal data about 'third parties' who are in contact with the service user, but who may not be Telecare service users themselves. The illegitimate misuse of sensitive personal data could put the person with dementia and others at considerable risk. Without wishing to sound flippant, electronic door entry codes could be passed to burglars. In addition to vetting the calibre of Telecare staff, there may also be a case for introducing a confidentiality clause in any employee contract, similar to the Official Secrets Act in the Civil Service.

There are related ethical issues concerning people with dementias’ views on general healthcare information exchange. In the Tracy et al. (2004) study, while there was general acceptance of the de facto legitimacy of inter-professional information exchange, there were reservations expressed about sharing healthcare information with the dementia respondents’ families. This reflects the
‘Right to Prevent Processing’ under the DPA (2008) which states,

‘Anyone can ask a data controller not to process information relating to him or her that causes substantial unwarranted damage to them or anyone else’ (Keen, 2007: 553).

The DHC professional will note that these legal rights to shape what can and cannot be disclosed about a service user have significant implications for ethical Telecare design:

‘To avail of the promised benefits of home healthcare, smart home inhabitants should be able not only to prevent unwanted disclosure of personal health information but moreover, to share the most meaningful details of information with different recipients in different contexts [My Emphasis]’ (Rashid et al., 2007: 188-189).

This leads to a consideration of the related ethical question of Telecare ‘response protocols’.

### 4.4.2.1 Data protection and Telecare Response Protocols

Brownsell et al. (2006:10) point out that an acceptable Telecare ‘response protocol’ requires sensitive consultation and negotiation:

‘Attention must also be given to defining protocols for the passing of information. For example, if an older person has a non-injury fall, should a relative be automatically informed? Some older people are reluctant to have such information provided to relatives, who may then suggest a move to institutional care’.

It is therefore no surprise that in his evaluation of the ‘Safe At Home Project’ for people with dementia, Woolham (2006a) found that developing a ‘social protocol’ to suit everyone was not straightforward. This is because the question of ‘who, under what circumstances, is to be contacted for a range of pre-specified situations’ can be difficult to negotiate. For instance, users with dementia may not want their families knowing about false alarms or non-injurious emergency situations, as this could lead to a re-appraisal of the their coping skills.

The ‘Aztec Project’ for people with dementia (Dunk & Doughty, 2006) pays very careful attention to how the Telecare ‘Call Centre’ responds to potential or actual home emergencies. As well as 'standard protocols' there are individually tailored protocols which have to be negotiated with service users and carers. This requires a careful imaginary journey through various domestic scenarios, involving the user with dementia as far as possible and his/her support network. The Telecare Response Centre staff are trained to strictly adhere to such protocols in organising the best response.

But in practice, however conscientiously we respect data privacy preferences, these may have to be overridden ‘where the law or the public interest …overrides a person’s right to have information
kept confidential’ (Scottish Office, 1989 cited in Clark, 2000: 88). In any case, the Data Protection Act 1998 (Schedule 2(4)) permits any data processing that is necessary to 'protect the vital interests of the subject' such as in medical emergencies. In practice, service providers such as Hanover Telecare therefore stipulate that the discretion of the operator has to be upheld as a clause in its 'Telecare Service Contract':

'Hanover Telecare shall, upon receipt of an alarm call or by verbal instruction, immediately contact your key holders, next of kin, doctor, or emergency services at our operator's discretion to arrange appropriate assistance for you and to provide follow-up reassurance calls when required.'

Confidential data on the service user such as a history of aggression or sexual offences may also have to be obtained for monitoring the safety of home workers. In this case, a data confidentiality over-ride clause would also have to apply, for any health and safety situations involving service providers as well as service users. In all such cases, any decision making by a Telecare Operator has to be clearly documented for accountability purposes.

The end result of such 'Response Protocol' negotiation should be a 'Telecare Plan' which the DHC professional may have to coordinate with a general Community Care Plan. A sample outline of such as plan is now proposed for the DHC professional (next page):
### Figure 22: Sample Telecare plan for a home based service user with dementia.

**Personal and Official Details...**

<table>
<thead>
<tr>
<th>Hazard</th>
<th>Possible Risk</th>
<th>Degree of Risk</th>
<th>Plan of Action to address risk</th>
<th>TELECARE RESPONSE PROTOCOL &amp; ESCALATION SEQUENCES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking indoors</td>
<td>Falling</td>
<td>High</td>
<td>Keyholder 1 to oversee recommendations from Occupational Therapy home safety assessment. Monthly visit by nurse from Falls Clinic. If no keyholders available, contact Responders.</td>
<td></td>
</tr>
<tr>
<td>Walking outdoors</td>
<td>'Wandering' at night</td>
<td>High</td>
<td>Door exit sensor set between 8PM and 8AM. If activated, call Responders. DO NOT CALL KEYHOLDER.</td>
<td></td>
</tr>
<tr>
<td>Gas Cooking</td>
<td>Escaping Gas</td>
<td>High</td>
<td>Gas isolation valve CO monitor to Telecare. Call TRANSCO If all clear, request CORGI registered Engineer to Gas safety check and restore supply.</td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td>Fire</td>
<td>Medium</td>
<td>DHC professional to regularly review Telecare Calls History Establish speech contact with resident. If no speech, call Fire Brigade. If self-report is OK, call Fire Brigade on second activation. Obtain report from Fire Brigade. If smoke alert is non-injurious and not serious, DO NOT INFORM KEYHOLDERS.</td>
<td></td>
</tr>
</tbody>
</table>
### Turning on Taps

Possible flood and ingress to downstairs neighbours

Flood detector proposed in bathroom

Install Electronic stop cock
Telecare Service to contact downstairs neighbour, Keyholder 3.

### Inactivity

Non-communicable accident or distress

Passive infra red monitoring
Bed absence monitor triggered after 30 mins absence, only between 11:30 PM and 8:30 AM.

If bed absence monitor triggered, theTelecare operator will speak to the service user via the voice module or Telephone.

If no response, contact Keyholder 1
If no response, then contact Keyholder 2
If no response, then contact police.

No remote Telecare intervention required.

### Uninvited Visitors

Bogus Callers

Door bell to be directly connected to mobile phone of Keyholder 2

No remote Telecare intervention required.

Based on 'Building On Strengths' (Alzheimer's Society, 2003).

#### 4.4.2.2 Data Integrity in Telecare Services

There are significant ethical concerns about data integrity in Telecare services. Data manipulation by staff can protect them from being blamed for decision-making errors, paralleling Norris' (2002) discussion of data manipulation to cover up malpractice in Telemedicine. This possibility presents ethical challenges to Telecare database designers who need to protect all data from unauthorised erasure, design audit trails and to review the data editing privileges accorded to various levels of staff (Tavani, 2004).

Finally, issues of data governance and Telecare services are clearly evolving with further questions remaining to be empirically researched.
4.4.3 Telecare’s interactions with the wider formal care system.

4.4.3.1 Telecare data for Community Care Assessment.

Telecare services generate forms of lifestyle visibility and audibility, generating potentially useful data for assessment and home care planning. Telecare data can be particularly valuable for domestic risk management in order to,

'... assess the frequency with which certain kinds of behaviour occur: for example the number of times that gas taps are left unlit, medication is not taken, or people leave their homes at inappropriate times' (Woolham & Frisby, 2002: 21).

Such data could complement conventional assessments which are often inadequate if they are just based on self-report from service users. This is because people with dementia may under-report or unintentionally misreport their needs (Meaney et al., 2005). In addition, people with dementia can be victimised by exaggerated accounts from neighbours and others about ‘wandering’, domestic fires or other putatively risky behaviour (Price, 2007b). Telecare services can therefore provide more objective data about significant domestic events to triangulate with accounts of service users and others. A sample summary of how Telecare data might feed into a ‘Home Care Plan’ is therefore presented in the following table (next page):
However, the DHC professional is reminded that the utility of Telecare data as a care planning tool has to be qualified by noted reservations about an over-reliance on ICT in the care professions generally. Database forms of knowledge can be privileged over more interactive ways of knowing the service user. For example, Parton (2006) laments that a 'narrative' way of interacting with an individual client has been superseded by 'algorithmic modelling' of cases in some forms of social work. This concern can be related to a general ethical malaise about ICT in 'managerial' social work where,

'...electronic assessments and records can be encoded by the discourse of efficiency rather than the situated and interactive nature of user-centred empowerment' (Postle, 2002).
4.4.3.2 The Interaction of Telecare with other ICT Trends for People with Dementia.

In the future, some people with dementia may retain ICT literacy skills far into the course of their condition. As Bryden (2005:119) puts it, 'I can bash away at the computer – and get a good laugh from the spell check'. In line with this appreciation of retained ICT skills (Marshall & Tibbs, 2006), there are an increasing number of ICT applications suitable for dementia users. Standard platforms such as a personal computer or mobile phone will carry a host of other information and support services to converge with Telecare. As the ICT literacy level in the population increases, such developments hold much promise for future cohorts of older people with dementia.

Some people with dementia are already welcoming online spaces as more validating than offline spaces, as noted in the rather sad irony of the following comment:

'I mostly live in social cocoon... When I venture out it is usually on the internet, not in so called real-time. I don’t want to be tedious, I don’t want to be pitied and I don’t want to be patronised' (Friedell, 2006:76).

For an ICT user with dementia, there are also clear advantages in the asynchronous pacing of communications in email lists and online newsgroups, since people with dementia can feel 'outpaced' in 'normal' everyday conversation (Bryden, 2005). ICT is also opening up many collective support and advocacy opportunities, if mental capacity permits, to promote the citizenship model of dementia (Marshall & Tibbs, 2006), such as through the 'Dementia Advocacy and Support Network International' (DASNI) (Bryden, 2005; DASNI, 2009) and the informal *dementia café* (Dementia café, 2009). Such online communities can stimulate standpoint epistemologies to contest 'old culture' versions of the standard 'dementia script' (Bryden, 2005). In this way, some of the negatively stereotypical views of dementia and ageing in general might be overturned through novel online formations. These social formations have interesting parallels with the de-stigmatisation of the Burakumin 'castes' in Japan, arising from their collective self-advocacy on the internet (Kirkpatrick, 2008).

However, while there is welcome space for anecdotal accounts as forms of peer support, there are clear ethical concerns about spurious information claims such as for 'wonder drugs' and 'miracle cures'. Such claims may not be subject to the stringent peer reviews and forms of quality control that information validation conventionally requires. The growth of online communities also means that participants may be subject to various forms of online abuse and scams, deceptive identities, undercover research and dubious commercial practices. Such risks may be particularly acute for
online participants with cognitive impairments. In the coming years as various ICT technologies converge, the DHC professional must be aware of such ethical concerns. It must also be acknowledged that the apparent white, middle class bias in online dementia communities so far, may need to be transcended (Marshall & Tibbs, 2006).

4.4.3.3 Telecare in the context of more older & dementia-friendly services.

The pioneering success of the ‘Home Safety Service’ (Bowes & McColgan, 2006; Bowes, 2007) in West Lothian has been partly attributed to its multi-disciplinary partnership model - an integrated system of community care, health and supported housing services for older people, with a lead role from the West Lothian Social Work Department. As achieved in the West Lothian model, there is general consensus throughout the UK that Telecare services need to be implemented through service partnerships. Yet, this is presenting considerable challenges in practice. As found in the ‘Safe At Home’ Telecare evaluation for people with dementia (Woolham, 2006a), there was wavering professional support for the project and disappointment in the relative lack of commitment from Care Managers in particular. One solution to barriers to Telecare implementation may be more awareness-training for professionals and the development of a more robust evidence base to convince them about the ‘business case’ for Telecare (Alaszeweski & Cappello, 2006). In any case, the jury is still out on how effective healthcare partnerships are for service users in general (Lymbery, 2005; Glasby, 2007). As yet, there seems no solid evidence that the internal benefits of better inter-organisational working are translating into improved service outcomes for older service users (Brown et al., 2003).

Even with effective and streamlined partnership delivery, initiatives such as Telecare are unlikely to succeed if the formal service surround is adequate. In a rather pessimistic projection, Loader et al. (2007) therefore claim that the delivery of Telecare will be hindered by the drivers of ‘marketisation, bureaucratisation and managerialism’ in the formal care services. Such trends are frequently criticised in the literature as having downgraded the status of holistic models and ethical caring in social work practice generally (Lloyd, 2006). And since formal services can be vital for supporting vulnerable service users and their informal carers, any Telecare services are unlikely to compensate for ongoing shortfalls and deficiencies in home care and other support services.

The DHC professional will also be aware that despite progress towards multiply-partnered ‘Single Shared Assessment’, holistic assessment for a complex bio-psycho-social condition as dementia is not always carried out. Instead, assessments are still frequently criticised as being resource driven.
and mechanistic, instead of service user focused. Such short term, procedural assessments with a services-eligibility focus, are criticised by Ray & Phillips (2002) as clearly unethical for someone with dementia. This is because insufficient account may be taken of goals and strengths as well as the more obviously presented cognitive impairments and communication difficulties. By contrast, good assessment practice means that enough time has to be allowed for communicative rapport to match the ‘pace’ of the client and way-mark a relationship of trust with a professional ‘stranger’.

But even the most ideal holistic assessment cannot guarantee the quality of the resultant home care services. In particular, the DHC professional will be aware that the roll out of Telecare takes place in the context of much criticism of domiciliary care services for people with dementia and for older people in general (Curtice et al., 2002; Francis & Netten, 2004; Alzheimer Scotland, 2007; 2008). This criticism has persisted despite officially prescribed quality standards such as the National Care Standards for Care at Home (Scottish Executive, 2004).

Furthermore, this services’ dissatisfaction takes place in the context of criticisms of persistent structural disadvantages to older people in society. Accordingly, Cheston & Bender (2003) argue that more dementia-friendly services are part of an older –friendly service culture as a whole:

'We cannot separate ... the care that people living with dementia in their own homes needs from the wider needs of older people in general for a caring society, a decent pension, affordable heating and so on' (op. cit, 256).

Despite the generally perceived benefits of community care, older people are still discriminated against because of structural inequalities in the welfare system (Ray & Phillips, 2002). As a result, according to Adams et al. (2002), older people are more likely to be poor, disabled, badly housed and widowed. Having dementia may also compound such age-related structural disadvantages and it is ethically significant that factors such as education and health inversely correlate with the likelihood of developing this condition (Cheston & Bender, 2003).

Finally, it is not just the right surrounding services and structures that are a prerequisite for ethically acceptable Telecare but the promotion of a more older-friendly and dementia-friendly culture. Too often, people with dementia are oppressed by ill-informed cultural misrepresentations of ageing minds (McColgan, 2004). Feeding such misrepresentation are entrenched social attitudes and practices which constitute subtle forms of ageism (Lymbery, 2005). Even official discourses on the encouragement of ‘personalisation’, ‘independence’, ‘self care’ and the ‘expert patient’ (sometimes enlisting the support of informal carers), can be oppressive and therefore need to be subjected to ongoing critical scrutiny (Lloyd, 2006; Ferguson, 2007; Scourfield, 2007).
Given these considerations, the DHC professional will appreciate that the promotion of an ‘older friendly’ service culture for people with dementia is part of an ethically optimum milieu for Telecare services. It therefore seems fair to opine that the development of Telecare services will be either impeded or promoted by the dementia-friendliness and older-friendliness of the surrounding formal care system and culture.

4.4.3.4 Example 6: Current ethical challenges suggested by Telecare implementation in England.

The DHC professional will see that in the intersection of Telecare, dementia home care and ethics, there are still a lot of ‘loose ends’ which need to be addressed by more empirical work. The following example attempts to highlight for the DHC professional some of the ethical opportunities and challenges of Telecare implementation, as these are currently understood. It is hoped that further illumination will be provided by the ‘Whole System Demonstrators’ (Department of Health, 2008) in England which will examine the various systemic dynamics of Telecare and Telehealth services.

The ‘Preventive Technology Grant’ (PTG) 2006-2008 has been made available in England to all ‘Councils with Social Services Responsibilities’ (CSSRs) to support their efforts ‘to develop the use of ‘Assistive Technology and Telecare’(WOolham et al, 2007:1). In a survey of current implementation in England, a cluster of six objectives for Telecare providers predominated:

1. Enable vulnerable people to remain living independently for longer in their own homes, either by managing risks to independence, or promoting safety and security;
2. Delay or prevent permanent admission into residential and nursing care;
3. Prevent unplanned, avoidable admission to hospital;
4. Prevent unnecessary delays in hospital discharge;
5. Support carers and reduce carer stress;
6. Contribute to local falls strategies and the prevention of accidents in the home.

(Woolham et al., 2007:6).

These objectives accord with UK Community Care policy generally (Audit Commission, 2004b), with different emphases in the devolved administrations. But the current implementation of Telecare in England is by now means unproblematic. Woolham et al. (2007) have outlined some ethically relevant implementation ‘barriers’, to which this author has also added other relevant comments:
In relation to Telecare information for the public sector, Woolham et al., (2007) note a high dependence on private suppliers for information about Telecare, in preference to more ‘impartial’ Government and Public Sector sources. This may lead to bias and over influence of the public healthcare market by commercial suppliers. Woolham et al. (2007) therefore urge the development of more Telecare training and critical awareness by local authorities:

'Whilst a manufacturer or retailer may wish to sell as many telecare devices to local stakeholders as possible, it may be better for local authorities to use the PTG [Preventive Technology Grant] instead to invest also in training and development, thereby improving local knowledge – an important component of an effective local infrastructure for using A.T. and telecare' (Woolham et al., 2007:17).

Taking these lessons on board, a systematic approach to professional training is also being co-ordinated by the Joint Improvement Team in Scotland (JIT, 2008b).

• The relative lack of awareness of Telecare services may be affecting some professions more than others. For example, a recent report points to a relative lack of awareness of Telecare by Community Mental Health Teams compared to other professionals (National Audit Office, 2007). This is potentially serious, because all relevant professions need to have a say in any ‘proactive ethical’ (Baldwin, 2006) deliberation on Telecare services and dementia.

• The ‘inconsistent support’ from senior managers for Telecare projects is particularly highlighted. This means that many potential service providers are still not convinced of the ‘business case’ for Telecare. Similarly, people frequently report the lack of enthusiasm by Primary Care staff and GPs in particular for 'Telehealthcare' projects on their patch (Advanced Telecare Users Group, 2008). Such barriers may be partly due to the overall paucity of evidence for the effectiveness of Telecare systems to date (Barlow et al., 2006; 2007; Hendy & Barlow, 2008).

• Where different healthcare professionals do come on board, there are cultural challenges observed in partnership working which may be more to do with more generic ‘joint working’ issues. This is regrettable as the ‘synergy’ of partnership working is seen as fundamental to the success of Telecare (Audit Commission, 2004b). The main ethical challenge at the moment seems to be the projected distribution of costs and benefits between participating
agencies in Telecare projects. Any cost savings in preventive care seem likely to accrue to the Health Services initially. This is seen in some policy circles as a significant hindrance to joint working (National Audit Office, 2007). Justice requires that mechanisms have to be in place to ensure that any economic benefits are fairly apportioned between health, social services and housing support services. It is significant that in Scotland, fair apportionment of the costs and benefits of Telecare services between agencies, is also a key ethical concern (Joint Improvement Team, 2008a, b).

- There are concerns about the cost and service quality implications of demands on Telecare Response Centres to handle increased data loads as well as voice loads. This process may use up the lion’s share of local budgets leaving little funding for the ‘social response’. The sustainability of some smaller Telecare projects is also questionable when the current grant funding across the UK dries up by 2010 (Advanced Telecare Users' Group, 2008).

- There is regret that some potential beneficiaries of Telecare are excluded for consideration because of stringent ‘Fair Access to Care’ (FACS) criteria, where subsidised home care services are only delivered to people assessed as in ‘critical’ or ‘substantive’ need. This is despite the observation that,

> 'Evidence suggests that telecare development should be focussed on those in the lower and middle, rather than high frailty groups in order to have the greatest impact on subsequent moves into care homes' (Poole, 2006:16).

Although there is additional ‘Supporting People’ funding for Telecare in Sheltered and Supported Housing, people at home can still miss out on other main funding streams. Woolham et al. (2007) opine that a private market will need to be stimulated for those self-funders who fall between the two stools of social services support and Housing Support services. There may be some role for ‘direct payments’ here, though the uptake of direct payments by people with dementia is still seen as very low compared to other service user groups (National Audit Office, 2007). The development of a private market is also hampered by a lack of consumer awareness’ about Telecare, yielding calls for far more publicity (Joint Improvement Team, 2008b). According to Woolham (2007) more public awareness raising and education therefore needs to be carried out. There is also a strong case
for more demonstrator projects such as the ‘Norwich Smart House’ (Faife, 2006), and the ‘Aztec Project’s’ touring bus in Croydon, where prospective consumers can try out the technologies. Similarly, raising public awareness of Telecare services through media campaigns is part of the Telecare Strategy in Scotland (Joint Improvement Team, 2008b).

- Finally, whether the current English difficulties are just ‘teething problems’ or demonstrate more serious ‘implementation deficit’, remain to be seen. Further illumination will be provided by the wave of local Telecare evaluations in England expected later in 2008. Also welcome steps towards evaluation are the 'Whole System Demonstrator' Projects currently being initiated there (Dept. of Health, 2008).

4.4.3.5 Example 7. Author’s Own Practice: Are Telecare services really appropriate for some forms of dementia?

Although there is very little empirical detail available on how service users with dementia are interacting with Telecare services, the following reflections are based on this author’s own experiences as a Telecare Operator. From personal practice, Telecare services are perceived to be beneficial for the majority of those service users known to have dementia, where people are in distress due to falls or illness, or are unable to communicate about any home hazards. There is a defensible ethical argument for more provision of such services especially in rural areas. The DHC professional may note that in Scotland, urbanised communities have a much higher penetration of Telecare services for people over 65. For example, Falkirk has about 42% penetration compared to about 8% for Argyll & Bute (Joint Improvement Team, 2008c). It is expected that this ‘post code’ lottery of Telecare services will also be addressed in the ‘Scottish Telecare Strategy’, as a matter of social justice. Far more people with dementia could therefore benefit from future expansion, particularly in rural areas where there is often considerable complementary social capital.

However, for a small minority of service users who have a medical diagnosis of dementia, one wonders about the appropriateness of any home Telecare services. These are frequent callers to the Telecare Response Centre who have learnt that pressing a personal trigger always activates a live human response, whatever the need presented. This is part of the way that Telecare service users often engineer human contact in any case, as Blythe et al (2005) note in their study of a mobile warden community alarm system:
The manager of the service noted that alarms were often not used for emergency calls but for company... Often ‘false alarms’ were not false alarms, they were reassurance calls’ (op. cit., 684).

Some users such as the ‘Victorian matrons’ seem to misuse the service for meals, shopping requests and 'yellow pages' information that the Telecare Operator does not have readily to hand. Other male services users, often apparently under the influence of alcohol, seem to enjoy sexual crudity and antagonise female operators. For ethical reasons, it is difficult to sanction such cases. The Telecare Operator has also to continually keep in mind that the Hanover ‘Service Level Agreement’ assures service users that ‘error or non-emergency calls will not prejudice the service provider’.

More disturbingly, it is observed that callers known to have dementia often present with forms of anxiety which are very difficult to allay over a Telephone. Emotional needs to realign with a past experience (lost parents, partners etc.) are frequently presented by people with dementia for which there can be no ready-made Telecare solutions. In such situations, Telecare Operators have to provide forms of quasi- 'Reality Orientation' (RO); yet even with adequate training, one wonders if this can have any value for more advanced dementias. This is because in more advanced stages of Alzheimer's disease, Anderson (2008h) argues that RO is practically pointless and ethically inappropriate as:

‘Fundamental alterations in consciousness and belief are as inevitable a consequence of hippocampal and cortical damage as paralysis is of spinal damage. The nature of the neurological impairment means that people... cannot be 'lectured' or 'coaxed' out of their cognitive impairments or 'drilled' back into 'agreed reality'’ (op. cit., 82).

Likewise, Meaney et al. (2005) in a community survey of service-use by people with dementia and their carers, highlight ‘persistent questioning’ as a key problem reported by 88% of the carer respondents. It is hard to see how any technological solution could help here; ‘simulated presence technologies’ could act as a distracter or ‘pacifier’ but their use is ethically questionable (Astell, 2006). Ideally, people who present in this way might benefit from more face to face care, and forms of intervention based on validation and resolution therapies (Stokes & Goudie, 2002). For instance, the plea of 'I want to go home' may really mean, 'I'm anxious and need assurance' (Adams, 2008g: 147), but the underlying need would only seem addressable through reliable face to face human contact.

Yet, in the absence of any direct human contact, Telecare may be the only 'lifeline' some service users with dementia will have. The responding Telecare operator, even if prompt and
compassionate, is rarely resourced to provide appropriate input. It is also noted that keyholder and formal responders are reluctant to attend such cases if the only need is deemed to be 'reassurance'.

From listening to such minority cases, though frequent, one suspects that some people are conveniently assessed for Telecare packages, but wider aspects of their well-being have not been taken into account; or their care plans, if they exist, are not regularly reviewed. Such people, as long as they are demonstrably safe and not a threat to themselves or others, can in some sense be 'contained' within the 'safety net' of Telecare but not really enabled by it, as discussed in Question 2 of this Thesis. Ideally, such service users might benefit from more direct social and carer input instead of technological services as discussed in Question 3. This ethical concern about some users with dementia which is shared by many Telecare staff, underlines the necessity for careful person centred planning as emphasised in Question 1 of this Thesis, though it is acknowledged that in DHC practice, resource constraints have to be taken into account.

This final reflection on personal practice as a Telecare Operator therefore brings this ethical investigation full circle. We are returned to the opening ethical challenge of this Chapter which the DHC professional must never stop asking: Is Telecare or any assistive technological service ethically appropriate for this person or this relationship in the first place?

137
CHAPTER 5

CONCLUSION

Based on our currently available knowledge, it is hoped this Thesis has illuminated some of the ethical intersections between best practice in dementia home care and best practice in Telecare services. The DHC professional should therefore be better informed and empowered to contribute to the social shaping of new technological services, although it is realized that much further research needs to be done. It is also acknowledged that the ideal case scenarios proposed in this Thesis may be difficult to reproduce in practice, because of inevitable resource constraints in the various dementia home care services. Nevertheless, in the interest of ‘proactive ethics’, it seems essential to define ethical benchmarks at the current time, in order to steer Telecare services in an optimally dementia-friendly direction.

There already exists a considerable bedrock of studies in the stand alone assistive technology field, which can yield transferable lessons for ethical Telecare design. However, Telecare innovations raise additional questions for which the existing empirical base is inadequate, hence the ethical interrogation of this study. Accordingly, the four main strands in the literature on Telecare which seem most salient to Dementia Home Care (DHC) professionals were understood to be:

- The harmonization of person centred care with user centred design in planning and implementing Telecare services;
- The possibilities of Telecare services for the further enablement or containment for people with dementia;
- The impacts of Telecare services on formal and informal care relationships;
- The ethical implications of the formal service re-configurations that Telecare is introducing.

For analytical clarity, these strands were treated separately in the body of this work. This Conclusion now attempts to inter-relate and synthesize the findings of this study before discerning a wider ethical panorama of further fieldwork for Telecare services for people with dementia.
The Thesis has been presented within the critical context of the 'new culture' versus the 'old culture' of dementia care. The former emphasizes sensitively customizing services around people with dementia and their carers. Yet, despite the community care developments since the 1990s, the DHC professional will be aware that formal services are still frequently criticized as deficient, piecemeal and uncoordinated. The roll out of Telecare services for people with dementia could therefore be impeded if the surrounding service system is inadequate. Fortunately, there are progressive signs in both the dementia and Telecare arenas - the forthcoming 'Dementia Strategy' in England and the 'Telecare Strategy 2008-2010' in Scotland. We need to dovetail the two kinds of initiative in the UK, so that a truly dementia-friendly Telecare system evolves. The 'Whole System Demonstrator' projects in England, examining how Telecare services are best integrated with other services, are therefore to be welcomed. It is also promising that the Telecare Services Association is producing a new 'Code of Practice' for Telecare service providers later in 2008, to accommodate the growing diversity of service users' needs. The Social Care Institute of Excellence is likewise producing a 'Code of Practice' for general Assistive Technological services for vulnerable older people. It is hoped that all these initiatives will pay sufficient and ethically sensitive attention to people with dementia and their carers.

Acknowledging the limitations of our current knowledge, it seems fair to say that Telecare’s automated and monitoring technologies, can promote both self-support and home safety for significant sub-populations of service users with dementia. This parallels developments in the general disability field, where assistive technologies have made great strides in correcting for deficiencies in mobility, strength, flexibility and sensory impairments. There are now analogous developments in technologies for cognitive impairments such as 'memo minders', 'medication reminders' and item 'locators'. If we view dementia as partly an information processing deficit, there must be a strong ethical defense of these cognitive aids to memory, orientation and comprehension, provided assistive technological packages are carefully customized. DHC professionals also have to pay serious attention to the growing evidence from home monitoring studies that some people with dementia at home seem far more purposively active than we had hitherto realized. This yields further opportunities for better customised home care packages.

In addition to 'cognitive prosthetics', enhanced home safety seems a huge bonus of Telecare services. This putative benefit is by no means lost on people with dementia themselves as the Alzheimer's Society’s canvassing of their views on 'safer walking technologies' seems to be telling us. And clearly home care monitoring technologies may have significant value in detecting situations of possible older-mistreatment or abuse, where older service users are not able to tell us.
Monitoring technologies can also be used to ensure that formal carer inputs are in line with any negotiated home care plan. As a result there is a strong ethical case for Telecare services in carefully designed risk management plans provided the multi-faceted nature of domestic and personal risk is carefully negotiated and assessed. But, any comprehensive risk assessment must also acknowledge that assistive technological services can create new, sometimes unforeseen, effects such as the possible psycho-social risks of Telecare examined in this study.

The independence-enhancing and safety features of Telecare are bound to have pay-offs for informal and formal carers as well. Given the high relational dependence of many people with dementia, keeping people safe at home is clearly not equivalent to care, though a necessary but insufficient component of it. While acknowledging that dementia care is often physically and emotionally burdensome, the convenience and respite attractions for carers from Telecare can override the more challenging ethical reflexivity that dementia support can require. Telecare deployed as an 'electronic safety net', could therefore increasingly be used as a convenient 'electronic shield' for some carers and DHC professionals should be alert to this possibility. As an ethical priority, the horizon of the socio-technological containment of people with dementia therefore needs to be continually scanned. And ethically sensitive professionals will be aware that some warning signs are already noticeable in Scotland! This is because some statistics on Telecare outcomes such as 'reductions in sleepover services' are already being trumpeted as 'benefits'. For this reason, DHC professionals need to be continually vigilant about any possible trends towards the stealthy substitution of human care by socio-technical services, especially where accompanied by the rhetoric of cost effectiveness and actuarialism.

Yet, this author has to acknowledge that given the changing demographics of British Society, there is legitimate concern that the supply of carers, informal and formal, will be unable to meet demand. This may mean that even if Telecare is successfully rejected as a convenient substitution for human care -and there are legal safeguards to bolster this- we may have to increasingly accept socio-technological complementarity as a de facto part of the home care mix. Telecare /assistive technological services seem here to stay and are set to expand with strategic steering and sophisticated marketing. Assuming future human care shortfalls, DHC professionals will have to play a pivotal role in blending such services with other essential inputs of the dementia home care mix.

Neither can the author be seen to be making the glib assumption that human care in the home is always best, notwithstanding the common assumptions about homes as 'Centres of Excellence’ in
the general Telecare literature. As a conceptual corrective, the social science literature warns about over romanticizing the connected ideologies of home and family since these can be oppressive of various forms of disability and difference. In addition, some people with dementia can find home care services intrusive and destabilizing and indeed might welcome any assistive technological innovations to enable more self-support.

But Telecare services on their own cannot counter the recalcitrance of ‘old culture’ attitudes and practices, especially in Primary Care. Too many people, lamentably even professionals, still see dementia as a proxy for dysfunctional old age. Likewise, public discourse on dementia is often infected with negative stereotypical representation. A strategic approach, such as planned for England, therefore needs to promote more awareness that dementia is not just a progressive medical condition requiring medication but also a form of social disability which can be co-managed by non-pharmacological means, including assistive technologies with appropriate social care. It remains to be seen how the English Strategy advances the ‘new culture’ of dementia care, as a guiding leitmotiv for Telecare services in England and the UK.

Finally, in the course of this study, the author has been continually reminded of gaps in our knowledge which have limited the scope and the warrant for some of the ethical findings suggested. We need far more empirical work from people with dementia themselves and their carers and significant others, on how they are experiencing existing Telecare services and where they see such services going. Good work is beginning to be done in the area of ‘wandering technologies’ and in some of the foresight studies cited in this Thesis, but there is scope for further work. It is expected that dementia-supporting Professionals will have a huge role to play in partnering such ethical reflection. To inform a more rounded ethical critique, it therefore seems that much more data is required, particularly in the following areas:

- We need more data on best practice in the variously evolving business models for Telecare. While most Scottish services are subsidizing Telecare for people in the critical or substantive ‘FACS’ bands, and some providers will have a free basic Telecare service for everyone over 65, there is considerable variation in charging for Telecare services. It is also noted that for some providers, Telecare funding has to be sought from out of hours’ repairs and other services, as a core Telecare customer base is not yet viable. Yet, people with dementia are set to be an increasing sub-population of formal service users. These will often present complex needs requiring specialist help, so we need more data on what kinds of
business models deliver the most effective ‘person centered care’.

- We need further investigation of how Telecare data can contribute to the process of Single Shared Assessment for vulnerable service users, given that conventional assessment for dementia is often criticised as mechanistic and snapshot.

- We need more anonymised data in the academic and public domains from Telecare service providers on patterns of service use. Academics may need to be more proactive in accessing Telecare services in line with the Data Protection Act 1998, while respecting the ‘commercial sensitivity’ of Telecare data in a surprisingly competitive field. More seriously, the fact that people with known diagnoses of dementia are presently a tiny minority of service users, may mean that there are problems with data subject identification. Ethical research clearance may therefore not be possible until the Telecare user group with dementia expands.

- We need more knowledge about the evolving skill set and training needs of Telecare Managers, Telecare Operators, formal responders and other staff, who often have to deal with complex cases in a rapidly evolving field.

- We need more data on the piloting of specialist Telecare centres for complex needs such as dementia, and the linkage of existing Telecare services with healthcare providers, NHS 24 and specialist dementia advice lines.

- Lastly but by no means least, we need to genuinely listen to the voices of Telecare service users with dementia on what a more dementia-friendly service system really means for them. Telecare and ICT services will have an increasingly significant role to play in creating novel forms of visibility and audibility of service users with complex needs. But this is not enough. For a small minority of service users with dementia, Telecare services alone cannot meet some vital emotional or home care requirements. 'Hearing the voice of people with dementia' will seem sadly ironic if Telecare services can hear the needs of its callers but the
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