‘An exploration of health and social care service integration in a deprived South Wales area’

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Appendix 1<u>Mary Williams case scenario- real journeys.</u>

Mary Williams is a 78 year old widow who lives alone in a small town. She has had admissions to hospital in recent years for some trips and slips, occasional exacerbation of her chronic obstructive pulmonary disease, cardiac problems and irritable bowel. She lives independently most of the time. Her hospital visits for her chest are every 6 weeks where she may see a nurse or a doctor. In between those she visits her local GP for an update on her medication and any other ailments and checkups. She's able to walk to the doctors and the local hospital for her appointments. At the moment she's organising her hospital transport to another hospital some 30 miles away for some planned day surgery. Her family aren't able to accompany her on this occasion because they run a small family business but her son will be there when she gets home.

She doesn't require any health or social services to visit her at home. For a few days after the day surgery her daughter in law and granddaughter will help her get up, have a wash, make sure she has breakfast, lunch and tea, clean the house until she's ready to take over her normal personal and daily duties.

Mary Williams is now 80 years of age and six months ago 'fell' in the doorway of the local post office. Now she's not sure if she fell on the step or she had what someone called a TIA. She's been getting the odd one or two over the last couple of years. Until then she was walking to town for her pension, shopping (what she could carry), washing and dressing herself, doing her own cooking, managing her own finances. She has over the last year taken to keeping a diary of events so that she doesn't forget the detail and knows exactly when bills need paying and when she needs to plan for her appointments.

Following her fall and admission to hospital (she was there for 2 weeks) she was lucky that she didn't break anything but her body is still bruised and she has lost confidence. She doesn't feel that she can go out alone. Anyway, her son has told her that she mustn't go out alone without someone to accompany her. She's not happy with him telling her what she should and shouldn't do but she feels he'll only worry if she doesn't do as she's told. Anyway, she's not sure about those two steps and the path to the gate. Her friend lives in the supported living complex just across the road but she hasn't seen her in a few weeks now.

She doesn't feel she can wash and dress herself at the moment. She can manage her face and her arms but she can't seem to progress to washing and drying the rest of her body. She can fill the kettle and make a cup of tea but she's afraid to stand in the kitchen for any period of time just in case she falls. She damaged her teeth when she fell and can't wear her teeth and since her hospital admission she's lost weight so she really needs to visit the dentist. She had soft food in hospital. Now her family bring her some toast in bed in the morning, leave her some soup in a flask for lunchtime and drop a meal over to her in the evening. Her daughter-in-law has suggested that she

might have to think about other arrangements for food in the future. She doesn't feel able to cook herself anyway she also damaged her glasses when she fell and needs to visit the optician.

She doesn't get up in the night, even though she had two children she's been blessed with a toned bladder. She doesn't have the energy to make her bed in the morning. Luckily she has a toilet downstairs which she can use in the day time but going upstairs is a problem and so she limits it to once a day. In fact her son has mentioned getting the bed downstairs so that she doesn't have to bother going upstairs at all. The only problem with that is that she likes to have a shower and that's upstairs. Her daughter-in-law or granddaughter helps her once a week to wash her hair and shower. The district nurse has been visiting once a week to see to her wound on her leg. So her granddaughter or daughter in law helps her shower the night before the district nurse visits.

She's not happy with that because she's used to showering once a day and having her hair done at the local hairdressers. It really needs a cut. Her son has suggested that he'll contact a local mobile hairdresser and she can visit instead.

Mary Williams is now 82 years of age and lives at home. Since a fall a few years ago she doesn't go outside unassisted. She's afraid to be left alone. So the son and daughter-in-law have developed a regime to help mam.

'Monday afternoon she goes up to my sister's shop.
Tuesday I go down and shower her,
Thursday i go down and sort her money out and I do whatever,
Friday afternoon she goes up to my sister's shop,
Saturday I go down and do all her tablets for the week apart from keeping her company. [dom.care agency]go in Monday, Wednesday and Friday for washing and dressing, changing the bedlinen. They prepare a sandwich for mum for lunch and give her breakfast in bed.
She goes to day centre once a week for me to have a rest'.

The family organizes her outpatient appointments ensuring that they are with her for the appointment. They shop for Mrs Williams whether for food, clothing or domestic items for the house. The family prepare meals for Mrs Williams and she eats with them when she visits. When the son and daughter-in-law wanted a holiday recently Mrs Williams had a week's respite in a local care home. Both are increasingly exhausted by this regime and wonder how long they can sustain it.

Mrs Mary Williams is 86 years of age she lives alone in a small terraced house which has 10 steps up to the front door. Its where she's lived for the past sixty years, lived with her husband, nursed him when he died and brought up her children. She was born and brought up in the same street. Her daughter and son –in -law live a few doors away but she works full time and has a grown up family. Mrs Williams has had falls in the past, suffered a stroke (cerebrovascular accident) a couple of years ago and so this has

resulted in her limited mobility. She also has problems with her blood pressure, some heart failure and arthritis. Her continence problems resulted from a combination of childbirth and her CVA. This all means that she needs assistance to transfer from bed to chair and chair to toilet. She cannot peel vegetables or reach the cooker to make a meal or a hot drink and so she needs help to live independently at home. Carers visit morning, lunchtime, afternoon and evening to meet her her activities of daily living e.g. showering, dressing and meal preparation. Her relationship with her daughter is strained. They love one another but her daughter is the main breadwinner and pops in once a day to drop off the evening meal. Mrs. Williams keeps her own company with exception to the one day she goes to the day centre and the occasional visit from her granddaughters every few weeks. Her daughter '*hasn't got time to speak to me'*.

Appendix 2

Attended By:

Scoping the Frailty Programme
Summary and Recommendations from Meeting held on 1st July 2009.

All Names of Attendees have been removed

Purpose of the Meeting:

At the meeting of 17th June the Frailty Board was asked to provide workstream leads with urgent guidance regarding:

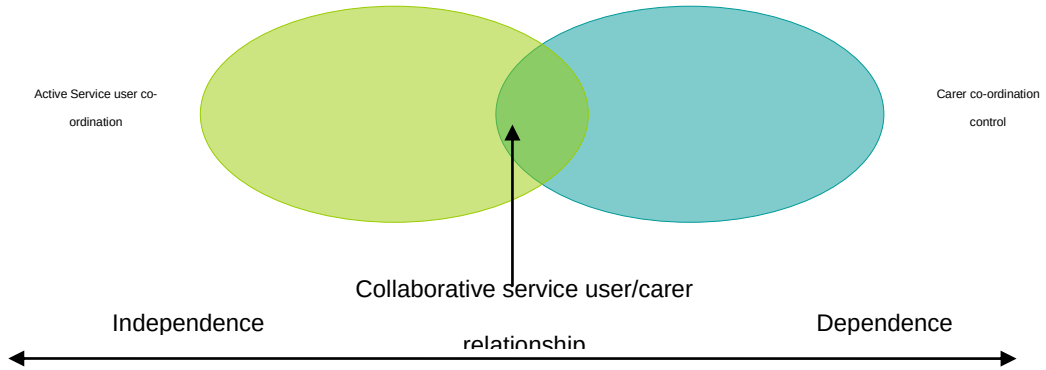
- What current services should be included in the Frailty Model for the purposes of the two-year programme e.g. ACAT, Rapid Response, Reablement, Emergency Care at Home etc?
- Are Chronic Conditions Management Teams, Falls Teams, Continuing Health Care Teams, and District Nurses included at this stage or just carefully aligned?

The Board was unable to meet that request and it was therefore proposed that the Strategic Vision Group (PK, DM and MW) together with AH, SM, NS, KB and LC should meet separately for produce a Recommendations Paper.

Service User/Carer Relationship Model

CW, Principal Lecturer, University of Glamorgan, had been invited to the meeting as she had used a very helpful model during the Workforce Development Workstream meeting, which it was felt would focus thoughts for this group task. The model is reproduced below:

Wallace.,C, (2009) An exploratory case study of health and social care service integration in a deprived South Wales area. Unpublished PhD thesis.



Active service user co-ordination- independent living- **OPD** (Linkages, consultative team)	Active service user co-ordination- supportive living –**CRT** (integrative team)	Collaborative relationship- **DH** (chronic illness) co-ordinating team; **OPD** (consultative team) and **CRT** (integrative)	Care Coordination control – **DH** (co-ordinating team) **DC** (parallel practice-linkages), **JDC** (multi-agency/disciplinary approach/co-ordinating)

Minimal carer input	⟷	Maximum carer input
Autonomous service user (SU)		Dependent service user (SU)
Confidante relationship	⟷	Carer relationship
Self -reliant SU		Not self- reliant SU
SU Privacy self-contained	⟷	SU Privacy not self-contained
SU Dignity self-assured		SU Dignity not self assured
SU choice dominant	⟷	Carer choice dominant
SU self-esteem maintained		SU self- indifference
SU fulfilment self determined	⟷	SU Fulfilment facilitated

Areas of Agreement:

It was agreed that the Frailty Programme will, by March 2011, deliver a locality based integrated service across the five boroughs.

Each locality will address

Prevention	Health & social care teams that bounce people back from crisis to independence	Longer-term care

	(out of the blue circle in the model above)	

For the purpose of the modelling required for the development of the Business Case, the Programme will focus on the middle section, that is health and social care teams whose primary aim is to promote functional autonomy.

However, it is stressed that this is part of the larger vision for service remodelling.

The health and social care teams as described in the Strategic Vision Document 'Happily Independent' will definitely include the following teams that currently operate, albeit in different ways:

- Urgent assessment
- Rapid Response
- Home Care Crisis Intervention
- Reablement
- Falls teams
- Voluntary sector where they are involved in the above e.g. the PATH programme
  (but will not be employed by the locality team).

Areas of Debate:

It was suggested that there should be a housing worker attached to each team but this was not fully debated.

There was a majority view that Mental Health Teams, Chronic Conditions Management Teams and District Nursing Teams should be closely aligned but not included in the integrated teams. However, there was insufficient consensus for the group to feel comfortable in making this a recommendation.

This led to further discussion as to whether the scope of the Frailty Programme should be broadened to link to the redesign of the service as a whole. Some possible risks and benefits of both approaches are outlined below:

	Risks	Benefits
Focused Scope (Health and Social Care Teams as Phase 1)	• Phased approach means impact takes longer to be realised; • Doesn't feel as radical as initially portrayed;	• Achievable within publicised timescales; • Financial implications more manageable; • Workforce

	• Programme gets subsumed by broader redesign work.	changes more manageable; • Consistency with Strategic Vision Document; • More sustainable from a change management perspective.
Broader Scope (Community Services Redesign)	• Frailty concept loses its identity within the larger piece of work; • Looks to stakeholders as if we've gone back on the original plan; • Increases preparatory work required NB financial and workforce considerations; • Increased change management issues; • Not possible within existing published timescales.	• Radical change in one big hit; • Fully aligned with Chris Jones' work so likely to get political buy in; • Eradicates the need to decide 'what's in and what's out' of the Programme!

Proposals for Resolution of the Debate:

Inclusion of Mental Health, CCM, and District Nursing Teams

It was proposed that this group reconvene in one week's time to work through the Mrs Jones' case study and use that to determine whether these teams need to be included in or aligned with the integrated and co-located health and social care teams.

Broadening the Scope

It was proposed that AH, AW, JA and LC meet within the next week to discuss the way forward with this element of the debate.

Actions:

- **LC** circulate these notes to the group for comment by close of business **1/7/09**
- **Group** to submit comments back to LC by close of business **3/7/09**
- **LC** to co-ordinate both meetings and circulate to group members.

APPENDIX 3

Leutz (1999, p83-110; 2005p 3-12) six laws of integration	**Lessons for policy and practice (NHS Confederation, 2005,p 10-12)**	**NHS Confederation (2005, p4) six factors for integration**	**Delnoij et al (2002) classification of integration**
1. **You can integrate all of the services for some of the people, some of the services for all of the people, but you can't integrate all of the services for all of the people**.(1999)'; '**Can we make integration easier?'**(2005). The concepts of linkages, co-ordination or full integration reflect the three levels of service user need.	**1.** **Don't start by integrating organisations.** Starting at team level or the patient pathway is more effective and less work. Although care must be taken when integrating disease specific pathways as they may fragment care.	1. **Organisational integration'**- how the organisation is structured e.g. merger or virtual	**Organizational Integration**-'on the meso level of health systems e.g. in the form of mergers, contracting or strategic alliances between health care institutions.' (Delnoij et al, 2002);
2. **Integration costs before it pays'**(1999); **'Support integration financially'**(2005). Integration happens best when start-up support, staff and support systems, new services or funding to existing services are added.	**2.** **Economies of scope and scale are hard to achieve.'** Quality of care will improve with co-ordination but they take time. Vertical integration of acute and community services are not always successful as the activities and ways of working are very different.	2. **Functional integration'**- how are non clinical support and back office functions integrated?	**Functional integration**-'refers to the cure, care and prevention aspects.'
3. **Your integration is my fragmentation'**(1999); **'Help not hassle physicians'** (2005). This law considers that physician independent contractor status is not helpful when considering integration.	**3.** **Cultural differences between sectors are a major issue'.** Cultures are different in hospital as opposed to primary care. The effects of cultural influences have been underestimated.	3. **Service integration'**- at the organisation level how are the clinical services offered by the organisation integrated with each other?	
4. **You can't integrate a square peg and a round hole'** (1999); **'Why is integration so**	**4.** **The right incentives'.** Clinicians have to be persuaded by the clinical	4. **Clinical integration**- at clinical team level, is care for the patient	**Clinical Integration**-'on the micro-level of

difficult?' (2005). Considers the differing models of health and social care and how integration should be considered from all aspects e.g. financial, differing providers, clinical orientation etc	argument as well as given financial incentives before the clinical benefits are felt.	integrated in a single process, both intra and inter-professionally through, for example, the use of shared guidelines along the whole pathway of care.	healthcare systems, i.e. continuity, co-operation and coherence in the primary process of care delivery to individual patients'(Delnoij et al, 2002);
5. **The one who integrates calls the tune'** (1999); **'Put the right person/organisation in charge of integration**'(2005). This considers the importance of shared goals, cooperation, inclusivity, the views of the service user and empowering service users to manage own budget.	**5.** **Be Patient'.** The amount of time taken to deliver integration is often underestimated. However when you consider the nature of the typology and the six factors required its not surprising that time is needed to achieve integration.	5. **Normative integration'**- the role of shared values in coordinating work and securing collaboration in the delivery of healthcare	
6. **All integration is local'** (2005). Only considered latterly, the use of Section 31 flexibilities moneys and local fit to integration based on need.	**6.** **Ensure that community services don't lose out'**. A difference in power relations on strategic boards often means that community services miss out on valuable resources.	6. **Systemic integration'**- the coherence of rules and policies at various levels of the organisation.	
	7. **Integrate for the right reasons'.** An attempt to integrate following merger, take over or acquisition in the United States has shown that failure is most likely.		
			Professional Integration- 'on the meso level of health care systems e.g. in the form of mergers (e.g. group practices), contracting or strategic alliances between health care professionals.'

Table Appendix 3: Comparison of Laws, lessons, factors and classification (Leutz,1999, 2005; NHS Confederation, 2005; Delnoij et al, 2002

Appendix 4 – definitions of integrated care: Table of classification of 34 definitions

Classification	Classification definition	Definitions	Mechanisms/techniques of integration
Clinical Integration (Micro- level) 4 definitions	'on the micro-level of healthcare systems, i.e. continuity, co-operation and coherence in the primary process of care delivery to individual patients'(Delnoij et al, 2002); 'and involves 'chains of care' and transmural care' (Billings and Malin, 2005)	*'a process to create and maintain over time, a common governance between independent actors in order to co-ordinate their interdependencies'* (Contandriopoulos et al, 2001, cited in Veil & Hebert, 2008 p76). *'when a comprehensive range of services is co-ordinated so that each user receives the right service at the right time by the right person without having to find it by him –or herself.'* (Demers & Lavoie, 2008, p6) *'A healthcare system which combines physicians, hospitals, and other medical services with a health plan to provide the complete spectrum of medical care for its customers. In a fully integrated system, the three key elements -physicians, hospital, and health plan membership - are in balance in terms of matching medical resources with the needs of purchasers and patients'* (Rygh and Hjortdahl, 2007, p4) *'a coherent and co-ordinated set of services which are planned, managed and delivered to individual service users across a range of organisations and by a range of co-operating professionals and informal carers'* (Van Raak et al, 2003, p11)	Co-ordination Co-operation Identifying individual need
Professional Integration (Meso-level) 5 definitions	'on the meso level of health care systems e.g. in the form of mergers (e.g. group practices), contracting or strategic alliances between health care professionals.' (Delnoij et al, 2002); 'refers to professionals within institutions working together' (Billings and Malin, 2005).	'Integrated care is when health and social care services work together to ensure individuals get the right treatment and care they need for their health concerns'(DoH, 2009a) 'in cooperation of the professionals of different disciplines and the elderly person, his/her family or friends, where health is conceptualised as the integration of mental, physical and social aspects as well as experiential ones.' Pahor and Domajnko (2008, p314) *'integrated care is multifaceted, requiring as it does a multi-skilled workforce to enable the seamless coming together of many different parts to meet complex needs' (*Billings and Malin, 2005, p51) *'organisation of professional people……who pool their means and resources to develop information, social and health care, and prevention services designed to resolve complex or urgent problems…working to a specific objective' (Frossard et al, 2004, p244)* *'integrated health and social care imply that the services are provided to all elderly- independent of where they live- by integrated teams of home helpers, home nurses (Colmorton et al, 2004, p143)*	Working together; (Transprofessional/ Disciplinary; Multi/ inter disciplinary, Disciplinary) Collaboration; Co-operation; Co-ordination Pooled resources

Classification	Classification definition	Definitions	Mechanisms/techniques of integration
Organizational Integration (Meso/macro-level) 12 definitions	'on the meso level of health systems e.g. in the form of mergers, contracting or strategic alliances between health care institutions.' (Delnoij et al, 2002); 'mergers, or networks forming between institutions' (Billings and Malin, 2005).	*'coordinated activities across organisational boundaries or holistic government* (Wilson & Baines, 2009, p17 *'integration is a mean to improve the services in relation to quality of health and social care' (Henrard et al, 2006, p2).* *'working together for market advantage. In health, it is used loosely to mean service co-ordination, linkage, care collaboration or multidisciplinary management' (de Jong and Jackson, 2001p71).* *'integration involves hospitals and the primary and community service sectors working together to establish and document systems that provide a smooth transition across sector boundaries that results in improved patient care, support for carers, better health outcomes, and optimal resource use'(Henderson and Associates, 2001, p vi)* 'a discrete set of techniques and organisational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and /or provider levels.' Kodner and Kyriacou (2000, p1) *'a set of services made available for a specific population group over a given geographical area, or for the population of a given geographical area, by a single company or organisation, grouped together under a single decision making authority' (Frossard et al, 2004, p244)* *' Seamless service chains are defined as an operating model, where the services received by the client and forming part of the service context within the social welfare and health care services and other social protection are integrated into a flexible entity..'(Salonen & Haverinen, 2004, p187)* *'integrated care is an organizational process of coordination that seeks to achieve seamless and continuous care, tailored to the patient's needs, and based on a holistic view of the patient'* Mur-Veeman et al (2003, cited in Ouwens, 2005, p142) *'co-operate and co-ordinate their activities in order to deliver care. Integrated care provision is also more demand-orientated, with supply following demand.'* (Paulus et al, 2005 p356) *'a discrete set of techniques and organisational models designed to create connectivity, alignment and collaboration within and between the cure and care sectors at the funding, administrative and/or provider levels'(Ex et al, 2004, p415)* *' a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion, Integration is the means to improve the services in relation to access, quality, user satisfaction and efficiency'(*Grone and Garcia-Barbero, *2001. p7).* *'a single system of needs assessment, service commissioning and/or provision. These arrangements are managed together by partners from health and social care, who nonetheless remain legally independent' (Thistlethwaite,2008,p17; 2004,p12)*	Partnerships; Networks; culture

Classification	Classification definition	Definitions	Mechanisms/techniques of integration
Functional integration (macro-level) 4 definitions	'refers to the cure, care and prevention aspects.' (Delnoij et al, 2002; Billings and Malin, 2005).	*'Demand orientated care …the supply of care should adapt to the demand for care, rather then making demand dependent on supply' (Ex et al, p417).* *'integrated care is a concept of rendering care services in which the single units act in a coordinated way and which aims at ensuring cost-effectiveness, improving the quality of care and increasing the level of satisfaction' (Grilz-Wolf et al, 2004, 117).* *'Joint working brings together health and social care to promote independence and improve quality of care for older people' (Coxon et al, 2004,p465).* *'informational, organisational and financial dimensions'*. Veil and Hebert (2008, p76)	Financial regulations protocols
Systems Integration (micro-meso- macro levels) 9 definitions	Refers to a citizen as defining own needs, services and outcomes in partnership with public service 'actors'.	*'a system that unifies care for physical and mental concerns'* (Butler et al, 2008 cited in Pomerantz et al, 2009) *'anything from the closer co-ordination of clinical care for individuals to the formation of managed care organisations (MCO)'* (Leutz, 1999 p77-78) and 'the search to connect the health care system (acute, primary medical and skilled) with other human service systems (e.g. long term care, education and vocational and housing services) in order to improve outcomes (clinical, satisfaction and efficiency) (Leutz, 1999 p77-78). *'a coherent set of methods on the funding, administrative, organisational service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goals of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex long-term problems cutting across multiple services, providers and settings.(* Kodner & Spreeuwenberg, 2002, *p3)'* *A whole system approach, which places the older person at the centre, will benefit older people by providing the right support, at the right time and by addressing the entire range of their needs. A whole system approach will also involve older people as partners – both as individuals who express their needs and help to define the outcomes they would like to see and as a group of citizens and users of public services who have a voice in the way that services are shaped and delivered. (Audit Commission, 2002p3)* *'a well planned and well-organised set of services and care processes, targeted at the multi-dimensional needs/problems of an individual client, or a category of persons with similar needs/problems....integrated care should be built up by elements of acute health care, long term(health) care, social care, housing and services such as transport and meals. It should also address empowerment of older persons, to enable them to live their lives as independently as possible'.(* Nies and Berman, 2004*p12)* '*Integrated care seeks to close the traditional division between health and social care. It imposes the patient's perspective as the organising principle of service delivery and makes redundant old supply-driven models of care provision. Integrated care enables health and social care provision that is*	Vertical integration Horizontal integration Networks. Pathways Collaboration, co-ordination case management

Classification	Classification definition	Definitions	Mechanisms/techniques of integration
		flexible, personalised, and seamless.'(Lloyd and Wait, 2005, *p7)* *'a single system of needs assessment, commissioning and/or service provision that aims to promote alignment and collaboration between cure and care sectors. The goals of integration are to enhance quality of care, quality of life, patient outcomes and efficiency of resources'* (Rosen and Ham, 2008, p2). *'implies that the complexity and content of an issue occurring locally in the organization of care are reflected in the larger environment' (Veil & Hebert, 2008 p76)*	

Table 1: Table of classification of 34 definitions: further developed from Delnooij et al (2002), Billings and Malin, 2005.

Appendix 5 – Ageing theories

Ageing theories	Description	References
Psychological Theories		
Maslow Human Needs	*'Five basic needs motivate human behaviour in a lifelong process toward need fulfilment'*	Maslow, 1954;
Jung Individualism	*'Personality consists of an ego and personal and collective unconsciousness that view life from a personal or external perspective. Older adults search for life meaning and adapt.'*	Jung, 1960;
Gerotranscendence theory	Critical theory of wisdom whereby there is a shift from the materialistic to the philosophical in a bid to achieve life satisfaction	Tornstam, 1989, 1996
Erikson Personality	*'Eight sequential life stages have corresponding life tasks.'* A developmental explanation	Erikson, 1965;
Levinson's theory of adult development	A stage theory of personality development. A developmental explanation	Levinson, 1978
Life Span development	*'Life stages are predictable and structures by roles, relationships, values and goals. Age group norms are an important part of life course.'* Three principles are as we age the benefits of evolution reduce, we need more culture, culture is not as effective as it once was. Selective optimization with compensation theory has its three mechanisms for ensuring that an individual manages ageing through selecting which domains one wishes to optimize abilities, maintaining reserves in order to maintain adequate function.	Baltes, 1987; Baltes & Baltes, 1990; Baltes & Smith, 1999
Socioemotional selectivity theory	A combination of selective optimization and compensation theory with social exchange theory. Individuals reduce their contact with some of their relationships whilst selectively increasing emotional closeness with others who are significant with them.	Carstensen, 1992
Sociological Theories	Also 'modernization theory', 'subculture theory', 'Social breakdown/competence theory'	Bengtson et al, 2005
Gerontagogy	Developed from an interdisciplinary approach to learning and Integrative Geragogy. This is a theory of guided learning for older adults, especially the oldest old which uses the re-actualisation of knowledge and wisdom to improve an individual's life satisfaction.	John, 1988; Maderer & Skiba, 2006a,b; Lemieux & Martinez, 2000.
Activity	'*Being occupied and involved are necessary for satisfaction late in life.'* Activity contributes to life satisfaction. The importance of ongoing social activity which as a result people develop a positive concept of self as a result of the activity.	Cumming and Henry 1961; Havighurst & Albrecht (1953), Lemon et al (1972), cited in Grossman & Lange, 2006; Bengtson et al, 2005
Social exchange theory	Dominated by the rules of reciprocity between individuals where individual resources are unequal as a result in a change of age related roles and abilities. This relationship only continues when	Dowd (1975) and Hendricks (1995) cited in Bengtson et al,

	the benefits outweigh the costs and where a better alternative isn't available.	2005; Ekeh, 1974
Social constructionist perspectives	Developed from traditions of symbolic interactionism, phenomenology and ethnomethodology. The focus here is on the individual meaning of age and the ageing experience and social behaviour.	Mead, 1934 cited in Bengtson et al, 2005; Berger & Luckmann, 1966; Garfinkel, 1967
Feminist theories of ageing	Gender is the principle by which social life is considered across an individual or population lifespan. It considerswomen's experiences of obligatory care giving, the domestic social structure within society and the status of unpaid work.	Stroller, 1993; Blieszner, 1993, Calasanti, 1999 cited in Bengtson et al, 2005
Disengagement theory	'*Gradual withdrawal from society and relationships serve to maintain equilibrium and promote reflection.*' Developed from structural-functionalism.	Cummings & Henry (1961,p14) cited in Burke & Walsh (1997).
Continuity theory	*'Personality influences life satisfaction and remains consistent throughout life. Past coping patterns recur as older adults adjust to decline and contemplate death.'* The theory reinforces the significance of a persons earlier life of lifelong disability with the aging process. Adapting to change is the overriding priority of individuals as they age.	Cohler, 1982 cited in Burke & Walsh, 1997; Atchley 1993, 1999, cited in Bengtson et al, 2005; Bigby, 2004;
Age stratification	*'Society is stratified by age groups that are the basis for resources, roles status and deference from others. Age cohorts share similar experiences, beliefs, attitudes, and expectations of life course transitions.'* A macro level theory with origins in structural-functionalism, a major concept is 'structural lag' i.e. a misfit between social structures and population and individual population changes. This is usually compensated by age-related policy changes.	Riley et al (1972) and Riley & Loscocco (1994) cited in Bengtson et al, 2005
Political economy of aging perspective	A multilevel analytical framework considers the state, sex/gender system, the public citizen and financil and post-industrial capital and its globalisation. All of which contribute to the construction of old age and its social policy.	Estes et al, 2001
The 'Lifecourse' Perspective	In order to understand the current age related social circumstances (including culture, location and context) of an older person then you must consider the major social and psychological occurrences that have occurred throughout the individual's life.	George, 1996
Biological Theories	Others also include 'somatic mutation theory', error catastrophe theory', 'gene regulation theory', 'rate of living theory', cross linking theory',' glycosylation theory', 'telomere erosion theory'.	Sandmire, 2010
Reliability theory	Damage to the system is accumulated over time even if it is built from elements which do not age because of the loss of elements which cannot be replaced	Garilov & Garilova, 2005
Neuropsychological theories of ageing	This comprises of theories of normal age-related change (related to cognitive function) and neurodegenerative change (degeneration of cognitive function which is observable e.g. Alzheimer's Disease).	Woodruff-Pak & Papka, 1999

Stochastic	***'Aging is based on random events.'*** These ultimately reach a state whereby life is unsustainable e.g. Somatic Mutation theory (genetic damage due to radiation exposure) and Error catastrophe theory (defect in error of protein synthesis). Both not well established.	Bengtson et al, 2005
Wear and Tear	*'Cells wear out and cannot function with increased aging.'*	Van Cauter, Leproult & Kupfer, 1996, cited in Grossman & Lange, 2005; Sandmire, 2010
Nonstochastic	***'Ageing is based on genetically programmed events.'***	
Programmed	*'Cells divide until they are no longer able due to shortening telomere which triggers apoptosis'*	Hayflick, 1985; 1996 cited in Grossman & Lange, 2005; Sozou & Kirkwood, 2001
Gene	*'Cells have a genetic programmed aging code'.*	Hayflick, 1984 cited in Grossman & Lange, 2005
	The following three are 'developmental-genetic theories'	
Neuro-endocrine	*'Problems with hypothalamus-pituitary-endocrine gland feedback system cause disease; increased insulin growth factor increases aging.'*	Finch & Seeman, 1999, Rodenbeck & Hajak, 2001 cited in Grossman & Lange, 2005 & Bengtson et al, 2005
Immunological theory of aging	The immune system declines as we age and as a result we experience an increase in autoimmune disease	Walford, 1969 cited in Bengston et al, 2005;
Free Radical	*'Membranes, DNA, RNA and proteins are damaged by free radicals with cause cellular injury and aging.'*	Harman, 1956 cited in Bengston et al, 2005; Grossman &Lange, 2006; Sandmire, 2010
	Evolutionary theories	
Mutation accumulation theory	Ageing is the result of the accumulation of mutated harmful genes.	Medawar, 1952 cited in Bengtson et al, 2005
Antagonistic pleiotropy theory	Genes are selected which are useful and give advantages during early life but harmful during later life. Built on the work by Medwar.	Williams, 1957; Sandmire, 2010
Disposable soma theory	Resilience in soma cells is reduced	Kirkwood, 2001; Sandmire, 2010

Appendix 6: Models and mechanisms of integrated care – an international perspective

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
Birmingham Own Health	Vertical integration coordination	Self care; health coaching; care manager	Long term conditions	2004	Primary and secondary care	Uk Birmingham	-	Rayner, 2009
PRISMA (Programme of Research to integrated Services for the maintenance of Autonomy)	Coordinated	Screening PRISMA-7 tool; Coordination at regional and local managers and decision makers (networks); single entry point; Case Management; individualised service plans; single assessment with management system; shared computerised clinical chart.	65 years +	1997-1999 pilot		Canada	Quasi-experimental design	Bravo et al, 2008; Hebert et al, 2008a, 2008b; Raiche et al, 2008; Kodner, 2006
Castlefield Model	coordinated	Integrated case management approach; hospital in-reach	65 years +	1999-2000 pilot	Primary care Health centre	UK (Runcorn)	Prospective comparative observational study	Keating, 2008; Lyon et al, 2006
ICCS (Integrated Care Coordination Service	Coordinated	Preventative service ; care coordinator	65 years +	2006-2007	Community home visits	Brent UK	Evaluation – time series	Mayhew, 2008
INTERMED	Coordinated	Decision support system: Systematic identification of service user complex needs for	Patients with multiple co-morbidities	-	Community	Netherlands	-	Latour et al, 2007

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
		case management (nursing) through nurse/ patient interview						
Unique Care	Coordinated vertically and horizontally	Southbury: Case finding high risk of admission; practice based register of service user with complex needs; integrated case management; hospital in-reach; 'Bespoke' care plan. London: Virtual team based at hospital (acute and community), GP practices and social services	65 years + Long term conditions	July-November 2006	Primary care practice	UK (Southbury (Enfield), London (Brent)	Evaluation Case studies (mixed methods)	Keating, 2008; Adam, 2006
The Darlington Project	Coordinated/fully integrated	Case management	Older frail people	1985-6	Hospital discharge into the community	Darlington, UK	-	Yaggy, 2006; Johri et al, 2003;.Challis et al, 1995; Challis et al, 1991a,b
The Gateshead Community Care Scheme	coordinated	Care management and primary care assessment/ intensive care management	Frail older people	1981-	community	Gateshead, UK	Quasi-experimental	Challis et al, 2002
PACE	Fully integrated	MDT. Case management; pooled financing;	55 years +	1987-1997 pilot, now continuous	Day health centre	USA		Chen, 2007; Kodner, 2006; Trice, 2006; Johri

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
		prevention.		programme				et al, 2003. Gross et al, 2004; Kodner & Kyriacou, 2000
Social HMO	Coordinated	Care management only	Older frail people	1985-1989 (S/HMO I); 1996 onwards (S/HMO II)	Short-term nursing home; day care; personal and home care	USA		Chen, 2007; Johri et al, 2003; Wooldridge, 2001; Kodner & Kyriacou, 2000
Community Support System	-	-	-	-	-	Japan	-	Chen, 2007
Long Term Care Resource Management Centers	-	-	-	-	-	Taiwan	-	Chen, 2007
SIPA	Fully integrated	MDT. Consolidated Case management; Interdisciplinary protocols; provider linkage	64 years + usually 75 years +	1998-2001 stage 1 & II; stage III	Community Primary care	Canada	Randomised Control Trial	Bravo et al, 2008; Chen, 2007; Kodner, 2006; Johri et al, 2003; Bergman et al, 1997, 2003; Beland et al, 2006; Beland et al, 2005

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
CARMEN (Care & Management of Services for older People in Europe Network	Thematic network of managers; Project 40 organisations – case study method	Development of a workbook for managers: Case management, MDT assessment, MDT, Joint care planning, single point of entry, shared ICT financial systems	Older people	2001-2004	European community	Belgium Denmark Finland Germany Greece Ireland, Italy Netherlands Spain Sweden, UK	-	Nies, 2006
Just-for –us	Coordination vertical and horizontal	Primary care, mental 6+alth, intensive/ care management, MDT and multiagency team. Disease management, discharge planning.	Frail adults on low incomes	2002	Community, Home visit	USA (Durham, NC)	-	Yaggy, 2006
On Lok	Comprehensive care	Case management by MDT	55 years+	Commenced 1971-date	Community, acute and primary care	USA		Johri, 2003; Yordi & Waldman, 1985; Bodenheimer, 1999.
ICON (Information, Care providers, One Care Management System, National and local values and principles)	Structured approach to developing vertical and horizontal integrated care	Single point of entry, unified records, multidisciplinary, multiagency	adults	2002 onwards	Primary community	Ireland, (Midland Health Board)	Case study	Tucker et al, 2004
Jefferson Health System (JHS)	Physician Cooperation (vertically	Care Management partnerships; centralised	Older people	1990s	Whole regional healthcare	USA (City of Philadelphia, New Jersey		Rabner, 1999

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
	horizontally and geographically). Integrated research, training, information technology, academic medicine	discharge system; care managers (nursing role)			system inc. acute, rehab, ambulatory, sub-acute, out-patients, long term care, day care centres, home care, primary care	& Delaware)		
Multi-dimensional needs assessment	Care coordination	Integrated medical and social care; Comprehensive assessment; Case management; MDT; care coordination	Frail older people	Trento 1995-1996 Vittorio Veneto 1997-1998	community	Italy (Roverto (Trento) & Vittorio Veneto);	Randomised control trial	Bernabei et al, 1998; Johri et al, 2003;
PROCARE (providing integrated health and social care for older people: issues problems and solutions)	Collaborative project of 18 models	Simultaneous case studies of two sites in each country (qualitative: interviews focus groups)	Older people		3 main types: discharge management schemes, case management projects, home care teams	Austria Denmark, Finland, France, Germany, Greece, Italy, Netherlands, UK		Billings, 2005; Coxon, 2005
Patient-oriented integrated care in Vienna (14^{th}-17^{th} district)	Cooperation between care providers and patient involvement and participation	Optimising communication processes through 4 inter-disciplinary and inter-organisational task groups: Integrate	Older people	2002-2004	5 Hospital departments; 4 GPs; 2 public health and social centres; 3 pharmacies;	Vienna Austira		Peinhaupt et al, 2004

Name of model/project	Model/ project Type	Mechanisms utilised	Target population	Dates	Setting	Country	Study design	Reference
		referral and discharge management; Integrated care for patients at home; diagnosis related integrated care; patient and family carers			1 occupational therapist			
	Coordinated Care Trials	Assessment, care planning, Enhanced GP role				Australia		MacAdam, 2008; Australian Government, 2007
Bois-Francs	-	-	Frail older adults	Pilot for PRISMA	Semi-urban community	Quebec Canada	Quasi-experimental design	Bravo et al, 2008; Tourigny et al, 2004

Appendix 7: analysis of intermediate care definitions using the adapted and developed classification of integrated care (Delnoij et al, 2002; Billings & Malin, 2005)

Classification	Classification definition	Identified questions	Intermediate care definitions										
			Oxford and Anglia Intermediate Care Project, 1997 (cited in JIT, Scotland, 2006-2009)	Steiner 1997 cited in Stevenson & Spencer, 2002,p7	Vaughan & Lathlean (1999)	Audit Commission, 2000,p21	DoH (2001b, p6)	NAW (2002, point 11)	Medway PCT & Matrix MHA (2003)	WHO (2004, p11)	Making Connections, 2006 cited in JIT, Scotland, 2006-2009	JIT Scotland, 2006-2009	HASCAS, 2008
Clinical Integration (Micro- level)	'on the micro-level of healthcare systems, i.e. continuity, co-operation and coherence in the primary process of care delivery to individual patients'(Delnoij et al, 2002); 'and involves 'chains of care' and transmural care' (Billings and Malin, 2005)	Is there identified interaction between service user and professional provision?					√						
		Are mechanisms of clinical integration identified?											
Professional Integration (Meso- level)	'on the meso level of health care systems e.g. in the form of mergers (e.g. group practices), contracting or strategic alliances between health care professionals.' (Delnoij et al, 2002); 'refers to professionals within institutions working together' (Billings and Malin, 2005).	Does it refer to professionals working together?					√	√					
		Are mechanisms of professional integration identified?					√	√					√
Organizational Integration (Meso/macro-level)	'on the meso level of health systems e.g. in the form of mergers, contracting or strategic alliances between health care institutions.' (Delnoij et al, 2002); 'mergers, or networks forming between institutions' (Billings and Malin, 2005).	Does it refer to organisations or services within health systems or across health and social care systems?	√	√	√	√			√	√	√	√	
		Are mechanisms of organisational integration identified?							√				
Functional integration	'refers to the cure, care and prevention aspects.' (Delnoij et	Does it refer to the functional aspects											

(macro- level)	al, 2002; Billings and Malin, 2005).	which support integration such as admin, finance, ICT?											
		Are mechanisms of functional integration identified?											
Systems Integration (micro-meso-macro levels)	Refers to a citizen as defining own needs, services and outcomes in partnership with public service 'actors'.	Does it originate with service user identified demand and the relationship to service provision?											√
		Are mechanisms of systems integration identified?											

Reference	Definition
Oxford and Anglia Intermediate Care Project, 1997 cited in JIT, Scotland, 2006-2009	"Intermediate Care can be described as those services that do not require the resources of a general hospital but are beyond the scope of the traditional primary care team. This includes: • Intermediate care which substitutes for elements of hospital care (substitutional care); and • Intermediate care which integrates a variety of services for people whose health care needs are complex and in transition. (complex care)
Steiner 1997 cited in Stevenson & Spencer, 2002,p7	'A whole set of services designed to smooth transitions between hospital and home, treat chronically or terminally ill people without recourse to hospital care and prevent long term institutionalisation' and 'that range of services designed to facilitate the transition from hospital to home, and from medical dependence to functional independence, where the objectives of care are not primarily medical, the patient's discharge destination is anticipated, and the clinical outcome of recovery (or restoration of health) is desired.'
Vaughan & Lathlean (1999)	This King's Fund definition of Intermediate Care as 'That range of services designed to facilitate the transition from hospital to home, and from medical dependence to functional independence, where the objectives of care are not primarily medical, the patient's discharge destination is anticipated, and a clinical outcome of recovery (or restoration of health) is desired'. They later added 'Those services which will help to divert admission to an acute care setting through timely therapeutic interventions which aim to divert a physiological crisis or offer recuperative services at or near a person's own home.'
Audit Commission, 2000,p21	'Services that provide rehabilitation between hospital and home. Such services provide rehabilitation to people who are medically stable, but who are not yet ready to return home after their discharge from hospital.'
Department of Health, 2001b p6	'Intermediate care should be regarded as describing services that meet all the following criteria: a. are targeted at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute in-patient care, long term residential care, or continuing NHS in-patient care; b. are provided on the basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery; c. have a planned outcome of maximising independence and typically enabling patient/users to resume living at home; d. are time-limited, normally no longer than six weeks and frequently as little as 1-2 weeks or less; and e. involve cross-professional working, with a single assessment framework, single professional records and shared protocols.'
NAW,2002 point 11	'are provided on the basis of a comprehensive assessment, (as defined within the Unified Assessment & Care Management system), resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery. The initial assessment should identify the appropriate

Reference	Definition
	clinician with managerial responsibility and the most appropriate care co-ordinator'.
Medway PCT & Matrix MHA (2003)	Most recently the "Intermediate care is a range of needs led, transitional and integrated services that are intended to maximise health gain and: • prevent unnecessary admission to an acute hospital bed; • support timely discharge; • reduce avoidable use of long-term care; • maximise independent living. These services are delivered in partnership between primary and secondary health care, local government services (in particular social care) and the independent sector."
World Health Organization (2004p11)	'A short period of intensive rehabilitation and treatment to enable people to return home following hospitalization or to prevent admission to hospital or residential care.'
Making Connections, 2006 cited in JIT, Scotland, 2006-2009	"A service provided on a short term basis at home or in a residential setting (usually about 6 weeks) for people who need some degree of rehabilitation and recuperation. It's aims are to prevent unnecessary admission to hospital, facilitate early hospital discharge and prevent premature admission to residential care"
JIT Scotland, 2006-2009	'Intermediate Care is a generic term that covers a wide range of services that help prevent unnecessary admission to hospital, or help facilitate early discharge'
HASCAS, 2008	**'**Intermediate Care refers to a configuration of care that provides short-term intervention to promote independence by maximising functional skills in relation to an individual's physical and mental health needs. Care and support should provide person-centred, needs-based care that holistically manages all of their physical and mental health needs. Care and support are based on comprehensive assessment, which lead to person centred, goal orientated interventions in the client's own home, a day setting or a bed-based unit for example. Assessment and intervention is provided by a range of professionals working within a shared framework of assessment, goal setting and documentation. IC services are time limited (individual need), although they may be provided sequentially or in parallel with each other the aim is to prevent prolonged hospital stays or inappropriate admissions to the acute sector or care home'

Appendix 8: Major findings of the literature review

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
Ahgren (2007)	Mixed methods: evaluation of two models, the 'unbroken chain of care' and the clinical functional integration : • A difficulty in measuring the level of interaction between the results as the results are based on multiple answers, they are sometimes ambiguous due to their interpretation. • Analysis can be influenced by other actors involved in the patient care e.g. nutrition and lifestyle	• It questions the possibility of creating a 'comprehensive evaluation model' which considers all the dimensions of integrated health and social care. • The clinical functional integration model had good construct validity, pragmatic validity and face validity. • The 'unbroken chain of care' was a good model for measuring quality from patient, professional and management.	• Repeating the measurements required for these models will give managers longitudinal data to help with reaching target levels of integration. • There is limited interest in repeating these measures unless there is knowledge of the target measures.
Ahgren & Axelsson (2005)	Quantitative: explorative study • The model of measurement focuses on the actual integration of health care units and not the perceived integration amongst health professionals. • The model is restricted to measure functional clinical integration. Therefore a high level of integration should not be equated with 'high quality integration outcome.' • The scales requires weighting when used with large numbers of the same or similar patient groups.	• Model of measurement is useful, reliable and valid measurement of functional clinical integration.	• Repeated measures would be an advantage.
Barton et al (2006)	Mixed methods: Postal surveys of Intermediate care coordinators, case studies with the whole systems of intermediate care, systematic review of evidence of effectiveness of intermediate care. • Response rate was low 46% for overall sample and 34% for PCTs. Although a response was received by each regional health authority • Limiting the systematic review to RCTs gave the study a very narrow perspective and restricted the researcher's ability to gain insight into other areas not yet subjected to RCT. • Three sites were within the same geographical area although treated quite separately. • Focus groups and one-to-one interviews are time consuming, questionnaires may be more practical. • Intermediate Care coordinators were responsible for identifying potential interviewees. Majority selected were more favourable in their views. • Level of missing data were a concern at the end of the intermediate care episode. Imputation methods applied. • Missing Reponses- either service user were not able to	• Six week limit of intermediate care too narrow • Services are mostly providing support for discharge as opposed to preventing admission • Intermediate care services are trying to integrate themselves into traditional service provision which will take time because of the 'adhoc' nature in which they developed. • Many services have problems in providing simple descriptive data. • Effective partnership working is the most important lever for development. • Obstacles to IC development included poor partnership working, insufficient or short term funding, staff problems • The benefits of IC in at home or in a home-like setting were perceived positively in contrast with hospital settings.	• A more focused survey of the nature and distribution of intermediate care sites in England, especially including diversity and rapid change. • Additional interviews with potential referrers to gain the whole system effect on how to improve access. • Interview intermediate care service users with the use of open ended questions to identify key issues and methods of improvement. • Quantitative data on what would truly have happened to service users if the services had not been present. • Quantitative- the true cost of

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	complete or the questionnaire had not been issued.		intermediate care, a bottom up approach to costs. • A longer episode of intermediate care (e.g. 12 weeks etc)- what would be the longer lasting benefits? • Developing a model to consider the health and social care economy that would allow the whole system capacity issues to be discussed.
Beech et al (2004)	Mixed Methods descriptive design: Patient case notes, suite of self completed questionnaires, workshops, semi-structured interviews. • Data quality- not possible to collect complete data for all relevant patients and carers. • Main source of quantitative data came from patient notes which although designed for the purpose were of variable quality. • Using a pragmatic design meant that it was not possible to reach some definitive answers about the scheme.	• Majority (57.0%) patients had needs for health and social care- contrary to prior professional beliefs. • Only 5.7% patients were re-admitted for acute care. • Overall, a positive attitude to the service although patients and carers questioned their ability to influence the choice of service provided. • 22.7% of carers were concerned about the quality of information about care.	• No methodological recommendations given.
Beland et al (2006)	Quantitative: RCT • No lead time to embed model before evaluation began • SIPA and control teams worked in the same agency and same building • Uncertainty about funding led to key staff leaving • Alongside the trials, there were significant increases in home care budgets, including the control group. • The study was powered to test for large differences 25-50% which may explain no significant difference. Whereas 10% may have been appropriate.	Integrated systems appear flexible. SIPA was cost neutral and changed the make-up of care through a reduction in nursing home and acute hospital use and an increase in community care. • 50% reduction in delayed transfers of care • No significant difference in utilization and cost of emergency department, hospital acute inpatient, and nursing home stays • No difference in total overall cost per person in both groups • SIPA caregivers experienced an increase in satisfaction, no increase in caregiver burden or costs • No difference in health outcomes	No recommendations.
Bernabei et al, 1998	Quantitative: RCT with 1 year follow up of an integrated social and medical care with case management intervention versus conventional care. • Randomly stratified by computer generated list of 200 people aged 65 years and over • Control Group (n=100) • Intervention group (n=100)	Community integrated social and medical care with case management cost effective in reducing admissions and functional decline. • Intervention group- admission to hospital or nursing home occurred later and less common; financial savings; improved physical function, cognitive decline reduced.	No recommendations made.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	• All members of staff patients and physicians were aware of which group patients were assigned, but blind about the outcomes of the study. • Case managers were intensively trained. • GPs may have introduced contamination bias as they sometimes treated both intervention and control patients.	• Control received more GP home visits •	
Bird et al (2007)	Comparative evaluation of an integrated care facilitation model. • Patient self selection • Data loss through failure to capture all of the patient's use of services pre-recruitment as they may have attended other hospitals and services. May have led to underestimation of beneficial impact of project. • Changes in recruitment criteria during the evaluation process	This model reduces demand of existing services through facilitating access to community health services and providing co-ordination between existing services. • Post recruitment (recruited patients)- 20.8% reduction in emergency department presentations; 27.9% reduction in hospital admissions; 19.2% reduction in bed days. • Comparative group (reclined recruitment)- 5.2% increase in Emergency department presentation; 4.4% reduction in hospital admissions; 15.3% increase in in-patient bed days.	• Real world scenario does not recommend a randomised controlled design. • The comparator group could be used to provide further information on impact of project such as recording peak times of hospital use.
Browne et al (1994)	Quantitative: a historic cohort analytic design of 5 groups. These were patient (and their carers) receiving rehabilitation at a community hospital, in-home services (home nursing care and hospitalization), two differently funded Community and health service centres with active and maintenance rehabilitation with groups social support and a group no longer requiring formal services. • Two thirds of clients did not complete the emotional portion of the OARS. • No client was in receipt of social assistance. • Not all caregivers were related to the patients participating in the study because of death, refusal, impairment. • Comparability is not ensured due to factors effecting the services are uncontrollable.	Community based rehabilitation centres can provide an excellent cost-effective alternative to hospital and in-home rehabilitation • Those patients (n=26) who partially completed survey were 'moderately to severely impaired'. Those that responded in full to the survey were 'better off' than those who did not respond. Which suggests that the problems faced by chronically ill people may be underestimated. • Carers report good physical function but only fair social and emotional function. They reported moderate levels of hardiness, social support, favourable meaning given illness, hope and purpose in life. Caregiver burden was highest in institutionalised patients. • Both clients and carers were economically poorer in the institutionalised group and tended to use more emergency services and community nursing services. • An inverse relationship between intensity of service and health care outcomes in all five groups.	• Further research to see if results reproducible.
(Brown et al, 2003)	Mixed Methods: Non-randomised comparative design- 1 integrated site and 1 traditional site. Main outcome measure was the number of people	393 older people recruited with a sub sample of 207 (53%) interviewed and standardised measures applied.	No methodological recommendations given.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	who remained living independently at 18 months from initial referral date. Secondary outcome measures were: Semi-strcutured interviews using Barthel Activities of Daily Living Index (BAI), the Abbreviated Mental Test (AMT), the Geriatric Depression Scale (GDS) and the Philadelphia Geriatric Center for Morale Scale (Angelicised version) (PGCMS). Observation, Patients notes. • Using opt out letters to recruit older people was supplemented by asking for consent to participate on first interview. • High refusal rate due to illness, frailty, relatives refusing on behalf of older person. • Not possible to carry out all the measures, some people were upset by the questions or it was considered inappropriate to ask the questions.	• This study does not give any evidence to suggest that the integrated site was more effective than the traditional site. • People in the integrated group were more likely to self refer or referred by family. • More people died in the traditional group than the integrated group. More people in the integrated group went to residential placement than the traditional group. • The integrated group were significantly more likely to be depressed than those in the traditional group. The traditional group had a higher quality of life although this result may be due to interviewer effect and increase in missing data.	
Burch et al (1999)	Quantitative: Single blind RCT with home assessments at baseline, six weeks and three months. To compare outcomes of day hospital to day centre rehabilitation • High number of unanticipated exclusions reduced the power to detect significant changes • Major problems in recruitment, compliance and drop-out due to death, illness and move to institutional care	• Improvement in functional ability and care-giver strain was similar in both groups. • Day centre rehabilitation was less popular due to stigma and practical difficulties. •	• Further research with this model is required to see if it can be replicated • Further research to see if care-giver strain is reduced in home based therapy • Also whether activities in day centre such as walking to the bus, meeting other people etc, also lead to improvement in function.
Burch & Borland (2001)	Mixed methods: Single blind RCT using Barthel Index, Philadelphia Geriatric Centre Morale Scale and Caregiver Strain Index at baseline (twice),six weeks, 3 months and one year intervals (in their own homes); random samples of 20 attendees at day centres were assessed and staff semi-structured interviews (n=9).: 1 day hospital (n=50) and 1social services day centres (n=55) with visiting therapists. • Patients with dysphasia were excluded because of communication difficulties with outcome measures. • Unable to interview participants due to lengthy and repeated outcome measure assessments and interviewer blind to treatment venue of trial patients. Would have led to contamination. • Design did not include a decision to investigate processes at the beginning of the study- this was thought of later after the study had started. • The localised nature of day care doesn't engender	• Significantly more disabled patients in trial group than regular day centre attendees according to Barthel Index (P<0.001), although no longer significant after three months. • The qualitative analysis demonstrated themes such as Negative assessments: weakness of day care model (discharge policies, perception of care standards, facilities at day centres, health and social care staff relationships, relationships of trial patients and regular day centre attendees, long term viability of day care model). Positive assessments: strengths of day care model (shared resources, access to different systems of care, health and social care staff relationships, relationship of trial patients and regular attendees).	• More qualitative data from participants would have been valuable. •

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	generalisation.		
Cornes et al (2006)	Qualitative: ethnographic evaluation in two phases: Phase 2- The evaluation of local commissioning, documentary analysis, workshops, telephone and face-to-face monitoring • Project continuity- The Intermediate Care Programme Manager from Help the Aged 1st phase became the research practitioner for phase 2. • Potential bias- the independent principal investigator from the 1st phase provided academic support and supervision in the 2nd phase.	• Phase 2: Only one project survived by demonstrating outcomes to both PCT and Help the Aged. Clinician controlled funding apparent. Co-location did not mean sharing the same overarching care plan. Difficulty in defining the role of the Voluntary agency especially when resources were tight in the statutory agencies. Trust was difficult but once attained relationship was invaluable. Voluntary agency seen as less professional and providing 'icing on the cake' which was non-essential. Commissioning not addressing whole system.	• No recommendations made.
Drennan et al (2005)	Evaluation – mixed methods. Semi-structured interviews (n=13), primary outcome measures using CANE (Camberwell Assessment of Need in Elderly) were unmet health and social care need, unmet financial needs, caseness on the depression and cognitive function scales. The secondary outcome measures were the number and range of referrals made by the team. • Did not include an economic evaluation •	• Multi-agency partnerships have the potential to improve the quality of older people's lives who are considered at risk by the GP.	• Feasibility with regard to costs needs further attention. • Further research –longitudinal effects of the implementation of health and social care services.
Enderby (2002)	Quantitative: Survey design of Community Rehabilitation teams • 97% returns (145) with 65% usable questionnaires (98).	• Broad range of skill mix with a broad educational and professional experience • Assessment of both patient and primary carer offered- focus on 'disability/activity'. • Biggest threat to CRT effectiveness is lack of attention to principles of teamworking.	No recommendations made.
Forster et al (1999)	Cochrane review Quantitative; random control trials (12) of day hospitals and alternative forms of care. • Random allocation with concealed treatment allocation only in 5 studies; further 6 studies probably had concealed allocation. • Lack of statistical power • Heterogeneity • 'Active' control with exception of three studies	• Day hospital effective but no more effective than alternative forms of care.	• Methods to record subject characteristics which influence prognosis and treatment processes should be well developed • Instrumental ADLs should be considered as outcomes. • Trials should be large, multi-centred or examine precise questions
Gill et al (2004)	Quantitative: RCT(n=188):: Intervention group (n=94); Self reported instrumental activities of daily living (IADLs), Performance Oriented Mobility Assessment,timed rapid gait and timed chair stands,Physical Performance Test: assessed at baseline, 7 months and 12 months. Resarch nurses blind to participant's assigned group.	• Participants in the intervention group (compared with control) experienced a reduction in functional decline through reductions in IADLs disability of 17.7% at 7 months (P=.036) and 12.0% at 12 months (P=.143); and improvements from 7.2% to 15.6% in mobility and	• No methodological recommendations given

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	• The control group (n=78) received 6 monthly visits at home from a trained health educator. Sessions were 45-60 minutes long and the health educator reviewed the participants health practices and promotion such as nutrition, management of medications, sleep, hygiene etc • 1/3 approximately of participants did not complete.	integrated physical performance at 7 and 12 months.	
Godfrey et al (2005)	Comparative case studies (n=5): Mixed methods – interviews with staff; non-participant observations; analysis of documentation; data on resource use; quantitative routine service data for 12 months; Tracking cohort with semi-structured data collection tool for 6 months; In-depth interviews with sub-set of service users and carers. • Generalisation from a limited number of sites and cases- theoretical sampling used and conceptual underpinning theories researched. • Conceiving IC as a system of care and not of individual services- underpinning theory of whole systems. • Considerable field research time spent collecting and verifying data. • Data quality generally poor, no common set of data definitions, held in many different ways (e.g. paper, electronic etc), this made accessing data, its accuracy and tracking clients difficult and sometimes impossible. • Drop out from tracking cohort due to communication and withdrawal of consent.	• A definition of intermediate care with purpose, structure, functions and content described. • 2/3 of people (64%) returned to their own homes on discharge from IC. • Important shifts in culture and practice were occurring. • Performance indicators did not show evidence of systematic changes in performance. • IC made significant changes in people's lives.	• Clear need for more consistent and reliable data. Also united data systems that build on the client's journey. • Out of pocket expenses by informal carers should be considered in future
Harwood & Ebrahim (2000)	Quantitative: two-phase experimental design. To measure the effects of attendance at a day hospital. • Non-randomised • Focus on patients attending for rehabilitation (74%) of day hospital population. • Missing data because investigator unavailable on some of the days patient's attended. • Length of stay determined by day hospital staff.	• Neither Barthel Index or London Handicap Scale changed when there was a short average stay of 9 visits and below. • Patients who stayed at day hospital for 10 visits and longer , London handicap measures were more sensitive to change than the Barthel Index.	• In order to gain a result which would be of statistical significance a large number of patients would have to be included in a trial. London handicap scale (4 points mean) requires a control group of 200 patients to gain 80% statistical significance. • To gain a 95% confidence interval at 1 point, this would require 1600 patients per group.
Holroyd, Twinn & Shiu, 2001	Qualitative; two-phase case study design of community rehabilitation network • Limited by exploring nursing only in a community rehab environment. Should have explored allied health professionals	• Nurses interpersonal skills highly valued • Concerns raised about lack of individual care	Study limitation- not including the allied health professionals who also give psychosocial care to the patients. No explicit recommendations made.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	influences as well.		
Malone et al (2002)	Quantitative: Before and after quasi-experimental design • Measurements as admission, discharge and three month post discharge	• 'From admission to discharge, significant improvements were seen in Timed Up and Go Test, Berg Balance Scale, and Geriatric Depression Scale (all P<or=0.002). From discharge to 3 months post-discharge, the Timed Up and Go Test, Berg Balance Scale and Mini-Mental Status Examination declined (all P<0.001) with no significant change in Barthel Index or Geriatric Depression Scale. From admission to 3 months post-discharge, Mini-Mental Status Examination scores declined (p=0.002) and Geriatric Depression Scale scores improved (p=0.007), with all other outcomes unchanged.'	• Lack of blind outcome assessment limited the study • Insensitivity of instruments especially Barthel, limited the ability of the study to detect changes in this group of people. • Larger group may have influenced result in respect of sustainability
Manthorpe et al (2006)	Qualitative: ethnographic evaluation in two phases: Phase 1- interviews (older people n=35; staff/ volunteers/ coordinators n=29), observations and case studies (n=100). To explore older people's experiences of using 7 pilot sites and their wider support systems.	• Phase 1: Older people very positive about their experiences. Six weeks of service is too short. A longer term model of monitoring and support with repeated contacts is suggested as a more appropriate model for frail older people. Practitioners should extend further into the care pathway to monitor risk of disabled people who are only receiving visits from volunteers. Voluntary organisations are an essential part of the care system.	• No methodological recommendations made.
Manthorpe & Cornes (2004)	Qualitative: Case studies: mixed methods including convenience sample of 5 service user interviews at each of the five sites. The aim of this part of the study was to see how older people engaged with practitioners involved in intermediate care and the views of the older people on the information they received. • Older people who have just come out of hospital are vulnerable and researchers have to be prepared for the interviews to be cancelled, shortened or difficult. • Terminology is practitioner based and researchers had to have a range of acceptable terminology. • New services built on previous experiences and past relationships were difficult to differentiate.	• Staff see themselves as having little time to engage with voluntary agencies to engage service users. • Service user goals were sometimes unrealistic, other emotional or physical factors such as lack of confidence or depression impacted on the ability to achieve goals; in addition to problems with communication as a result of shock, anxiety or physical impairment.	• No methodological recommendations made.
Martin et al (2004)	Qualitative: telephone interviews. • Low response rate due to structural re-organizations and intermediate care co-ordinators difficult to fins or not yet in post.	The following themes were realised: • IC provision cannot be easily categorized. • Provision is sensitive to local provision context and gaps in service. • Protocols for medical provision are well developed	• No methodological recommendations given.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
		as opposed to other professions • Further integration of intermediate care is needed • Precision vs flexibility in eligibility criteria. • IC health and social care strategies.	
McLeod et al, 2008	Qualitative: Telephone interview or postal questionnaire (n=17) service users; 10 case records per project (N=44 due to problems with selection); interviews project coordinators (n=5) • Samples selected randomly by project coordinators across their 5 projects.	• The health benefits of facilitating social network re-engagement is crucial to contributing to restoring and sustaining physical health and mental wellbeing. The process of social care was also critical. • The study confirmed necessary initial requirements such as assistance with 'low level personal care' needs to be integrated with 'intensive' intermediate care on an 'extended basis'.	No recommendations given.
Mackenzie, Carpenter & Kotiadis (2005)	Quantitative: No methodological issues are given.	• Standardised assessments are useful in describing health profiles of patients. • Shortage of services for cognitively impaired patients. • Patients fall into discrete groups i.e CART, day hospital, day care etc • With increased age and increased cognitive problems patients are more likely to be admitted to long term care services.	Further studies are required to provide the evidence based for strategic planning. For this a collection of clinically meaningful health care assessment data is required. These should be standardised country wide to enable comparison.
Moore et al (2007)	Mixed methods: Five case studies of intermediate care services. • Exercise could only be undertaken once due to the time it took to collect and validate the data. • Large loss of participants due to death, consent withdrawn by participants or their relatives, lack of accurate contact information. • Requirement of the medical ethics committee that the intermediate care staff approach the participants for consent and not the research staff.	• The five sites facilitated transition between health social care and other services. • Individual needs were taken into account when transferring people between services. • In the concept of intermediate care, joined up government goes beyond partnership working and in practice involves integrated service networks. • The care of the participants is shared between services.	• Although sample size was large enough for exploratory analyses further analysis is required to test these results.
Nancarrow et al (2004)	Qualitative: Focus group, interview, minutes of panel meetings. • The panel was not representative of the service users. Group members were 'activists and agitators'. Danger that it was a panel for personal concerns. • No time limit for panel participation and so gradually became service advocates rather than service user advocates.	• This ongoing provider led consultation is a transferable example of good practice.	• Marketing for the panel may attract more 'typical' service users. • Set clear time limits for service user involvement at the beginning.
Nancarrow (2004)	Qualitative: exploratory case studies: semi-structured interviews with intermediate care staff; documentary evidence.	• Two types of role overlap were perceived, horizontal and vertical substitution.	• No methodological recommendations made.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	• No methodological issues given.	• Increased clarity of each other's roles.	
Newbronner et al (2007)	Qualitative: multiple case studies (n=4) of homecare reablement services comprising of intake (n=2) and discharge support services (n=2); routine quantitative data for clients and interviews with managers • No baseline data for comparison • No control group • Not all groups collected all the same data	• Levels of understanding that referring practitioners have of reablement is important. • Reablement users fall into two categories: those who gain immediate/short term benefits and those who experience continued benefits. • Positive usage in homecare • 6 key factors influencing the impact of reablement e.g. carers perception of risk and service users attitude. •	• No recommendations given
Peet et al (2002)	Evaluation: six schemes (march 2001-April 2002). Multiple methods included documentation, Staff and service user questionnaire at admission and discharge and 3 month follow-up, in-depth interviews with service users (n=20). Retrospective data collection on service users for 5 months prior to prospective data collection commencing. Distinction made between acute care schemes (e.g. hospital at home) and reablement (rehabilitation). • Number of service users fitting narrow evaluation criteria, minimal • No comparator group • Data that health and social care practitioners collect in order to monitor schemes is different	• Average length of stay 15 days (7-9 for acute and 40 days for reablement). • ADL scores similar across schemes (Barthel) • Outcomes for service users positive overall. • Service users appreciated an alternative option to being in hospital with staff that were reliable, good communicatirs, met their needs, quality of care was excellent. • Scheme management differed and sometimes schemes did not have a single manager with the ability to make decisions. • Staff needed to maintain their professional links, competencies and developing skills • Difficulties in recruitment possibly due to temporary nature of posts • Experiences of joint working were positive, including joint multidisciplinary assessment • Difficulties in agreeing medical cover for the schemes	• To use a comparator group of people entering alternative services to intermediate care • To establish agreement across health and social care of data to be collated
Reid et al (2007)	Qualitative: Evaluation through Action Research using multiple methods. • Short term nature of the project for the collection of outcome and costs measurments. • The project didn't have a sufficient bedding down period and so the data collected may not reflect those of a mature team. • Staff had some difficulty with sustaining the use of outcome measures and would not be able to do so as routine practice.	• Developing trust between researchers and participants was gradual and was facilitated by the internal researcher. • Researchers could move freely up and down the organizational structure gathering information, unlike team members. • There were three themes; 'putting action research into practice', the influence of the research on the service implementation and the impact on the RLT members. These highlighted challenges to interdisciplinary team working, the care management	No recommendations given.

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
		approach and inter-agency working. These included role clarity, not fully utilising uni-professional skills, lack of preparation for role especially with inter-agency partners, fear of perceived lack of referral responsiveness. Respondents found the evaluation 'burdensome and scary'. • Once pilot finished the whole systems approach finished and interprofessional learning was reduced.	

Regen et al, 2008; Kaambwa et al, 2008	Two papers published from the same mixed methods case studies (n=5): semi-structured interviews(n=61) and focus groups (n=21) during 2003-2004. Participants were: strategic managers, IC managers, clinicians, health and social care staff.
	• using care coordinators to identify staff for interview- staff identified generally worked within IC and not in the wider services.
	• Did not interview service users- although a service user satisfaction survey undertaken (Regen et al, 2008).
	Quantitative- service data,Euroqol EQ-5D and Barthel Index and data
	• Some services did not provide the data on Barthel Index and Euroqol, because they did not routinely collect it. Barthel insensitive to small change
		• Themes
		  • Developing intermediate care-challenges, poor joint working, scepticism of clincians
		  • Benefits of intermediate care, patient centredness, working in a multidisciplinary team
		  • Weaknesses of intermediate care, shortage of staff, poor coordination between IC services
		  • Intermediate care needs to be part of a continuum of services
			• Explore other generic outcome measures as alternative to the Barthel

Ritchie (2003)	Qualitative: Adult day care (n=32): Focus groups and individual interviews.	• Adult day care is essential to the health and wellbeing of older adults and their care-givers. • Theses identified were respite, ageing in place, ADC programming, program characteristics, staff knowledge, skills and attitudes, northern perspectives.	No methodological recommendations given
Sviden et al (2004)	Quantitative (N=24) day rehabilitation and day centres: Sickness Impact Profile (SIP) and occupational self assessment (OSA) were undertaken as interviews to allow those with low vision to participate. • The small sample size make generalisation difficult and raise the possibility of risk of a type 2 error. • Validity and reliability of OSA- few evaluations and normative scores are lacking.	• The majority of people who attend these centres live alone and have severely restricted physical function. • Those who attended social day centre perceived better psychosocial function than those who attended day rehabilitation. • The centres serve as an important meeting place for severly disabled older people who would experience social isolation through being restricted in their own homes.	• Greater sample size. • Further studies on OSA are required. • Further studies on what support older disabled people require to participate in meaningful activities and to have a social life.
Townsend et al, 2006	Mixed methods case study to evaluate intermediate care at system, service and service user levels which focussed on the relationships between service users, carers and intermediate care services post hospital discharge. • Analysis using a grounded theory approach	• Patterns of caregiving relationships- 5 types, temporary carer, shared disrupted lives, reciprocal supporter through gentle decline, long term carer, caregiver as care receiver.	• A focus on handing over to mainstream services is needed

Author (s) and date	Methodological/ method issues	Results	Methodological Recommendations
	• Majority of carer interviews were joint, information gained may be different if interviewed separately		
Young et al (2005)	Quantitative; quasi-experimental design with embedded case control study. • Uptake of IC lower than anticipated which led to embedded case control study by matching 246 intervention patients with randomly selected control group patients. • Confounding of third variable (implementation of PCTs; seasonality) were thought to be negligible due to randomisation	• Intermediate Care (IC) not inferior to previous care system • IC group used more hospital bed days over 12 months • IC service clinically safe • Clinical outcomes, hospital and long term care use similar • Integration of IC with older people services had not been adequately achieved	No recommendations made.

Appendix 9: Study Questionnaire and Participant leaflet

Health and wellbeing questionnaire

Initials:			**Date of Birth:**		
Please tick which service you attend:	Outpatients	Reablement team	Day hospital	Day Centre	Joint day care

This questionnaire is about the way your health affects your everyday life

Please read the instructions then **answer by ticking √ once** only in answer to each question.

When you answer the questions, think about the things that you have done over the last 4 week and then compare it with your best health.

1. **In general would you say your health is:**

Excellent ☐ **Very Good** ☐ **Good** ☐ **Fair** ☐ **Poor** ☐

2. **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so how much?**

a. Moderate Activities, such as vacuum cleaning or bowling

Yes, limited a lot ☐ Yes, limited a little ☐ No, not limited at all ☐

b. Climbing several flights of stairs

Yes, limited a lot ☐ Yes, limited a little ☐ No, not limited at all ☐

3. **During the past 4 weeks, how much of the time have you had any of the following problems with your other regular activities as a result of your physical health?**

a. Accomplished less than you would like

All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

b. Were limited in the kind of activities:

All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

4. **During the past 4 weeks how much of the time have you had any of the following problems with your regular daily activities as a result of emotional problems (such as feeling depressed or anxious)?**

a. Accomplished less than you would like:

All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

b. Were limited in the kind of activities:

All of the time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

5. **During the past 4 weeks, how much did pain interfere with your normal day**

Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely ☐

6. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give one answer that comes closest to the way you have been feeling.**

How much of the time during the past 4 weeks…

a. Have you felt calm and peaceful?

Not at all ☐ A little bit ☐ Moderately ☐ Quite a bit ☐ Extremely ☐

b.Did you have a lot of energy?

All of the Time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

c.Have you felt downhearted and depressed?

All of the Time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends or family)?

All of the Time ☐ Most of the time ☐ Some of the time ☐ A little of the time ☐ None of the time ☐

8. Does your health stop you from getting around? (Tick one box only)

Not at all: I go every where I want to, no matter how far away ☐

Very slightly: I go most places I want to, but not all ☐

Quite a lot: I get out of the house, but not far away from it ☐

Very much: I don't go outside, but I can move around from room to room indoors ☐

Almost completely: I am confined to a single room, but can move around in it ☐

Completely: I am confined to a bed or a chair. I cannot move around at all. There is no-one to move me ☐

9. (a) Does your health stop you looking after yourself?

Examples include housework shopping, looking after money, getting dressed, washing, shaving and using the toilet.

Not at all: I do everything to look after myself ☐

Very slightly: I need a little help now and again ☐

Quite a lot: I need help with some tasks such as housework & shopping but no more than once per day ☐

Very much: I do some things for myself, but I need help more than once a day. I can be left alone safely for a few hours ☐

Almost completely: : I need help to be available all the time. I cannot be left alone safely ☐

Completely: I need help with everything. I need constant attention night and day ☐

(b) I have home care (or a carer) to help me look after myself ☐

Once per day ☐ Twice per day ☐ three time per day ☐ four times per day ☐ Five times per day ☐ or more ☐

10. Does your health limit your work or leisure activities?

Examples include housework, gardening, hobbies, going out with family or friends, watching television, reading and going on holiday.

Not at all: I do everything I want to ☐

Very slightly: I do almost all the things I want to do ☐

Quite a lot: I find something to do almost all the time, but cannot do some things for as long as I would like ☐

Very much: I am unable to do a lot of things, but I can find something to do most of the time ☐

Almost completely: I am unable to do a lot of things, I can only find something to do some of the time ☐

Completely: sit all day doing nothing. I cannot keep myself busy or take part in any activities ☐

11. Does your health stop you getting on with people? (tick only one box)

Not at all: I get on well with people, I see everyone I want to see, and meet new people ☐

Very slightly: I get on well with people, but my social life is slightly limited ☐

Quite a lot: I am fine with people I know well, but I feel uncomfortable with strangers ☐

Very much: I am fine with people I know well but I have few friends and little contact with my neighbours. Dealing with strangers is very hard ☐

Almost completely: Apart from the people who look after me I see no-one. I have no friends and no visitors ☐

Completely: I don't get on with anyone, not even the people who look after me ☐

12. Does your health stop you understanding the world around you?

Not at all: I fully understand the world around me. I see, speak and think clearly, and my memory is good ☐

Very slightly: I have problems with hearing, speaking, seeing, or my memory, but these things do not stop me from doing things ☐

Quite a lot: I have problems with hearing, speaking, seeing or my memory which make life difficult a lot of the time.
But I understand what goes on ☐

Very much: I have great difficulty in understanding what's going on ☐

Almost completely: I am unable to tell you where I am or what day it is ☐

Completely: I am unconscious and completely unaware of anything going on around me (answered by a carer) ☐

13. Are you able to afford the things you need? For example: your health problems may have led you to some extra expenses.

Yes, easily: I can afford everything that I need. I have easily enough money to buy modern labour saving devices, and anything I may need because of my ill-health ☐

Fairly easily: I have just about enough money. It is fairly easy to cope with expenses caused by ill-health. ☐

Just about: I am less well off than other people like myself; however, with sacrifices you can get by without help ☐

Not really: I only have enough money to meet my basic needs. I am dependent on state benefit for any extra expenses I have because of ill health. ☐

No: I am dependent on state benefits, or money from other people or charities. I cannot afford things I need ☐

Absolutely not: I have no money at all and no state benefits. I am totally dependent on charity for most of my basic needs ☐

Thank you very much for completing this questionnaire. Please return it in the stamped addressed envelope provided.

For any further information regarding this study please contact:

Carolyn Wallace, Associate Lecturer, School of Care Sciences, University of Glamorgan, Pontypridd, CF 37 1DL. Tel: 01443 483187

Appendix 9: Study Questionnaire and Participant leaflet

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your doctor if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

1. Study Title
Exploring Health and Social Care Services in the Community

2. What is the purpose of this study?
This study is an exploration of the services delivered in the Joint Day Care facility, [name] day centre, [name]day hospital and by the [name] reablement team. It is trying to understand how these services work, what differences they make to the lives of those who attend them and whether there are any differences between the services. The researcher is studying for a PhD and this will form part of her degree.

3. I don't attend any of these services.
You may have been attending an outpatient's clinic in Ebbw Vale hospital. If this is the case then you are included because the study needs to include people who do not attend any of these services but may suffer from similar problems. Including you will help us to understand the differences between the care that's given in each of the services.

4. Why have I been chosen?
The more people we have taking part in the study the more likely it is that we'll be able to believe and have an understanding of the results. We are asking all service users within these areas to complete two questionnaires. The questionnaires will include questions about your health, wellbeing and lifestyle. After the

questionnaires have been completed, a smaller number of service users will be asked to participate within an interview and they will be contacted once the results of the questionnaires are understood.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form (keeping a copy for yourself). If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

6. Who has reviewed the study?

The study has been reviewed by the [name] Healthcare NHS Trust Research Governance Committee's and [name] Research Ethics Committee. It is also being supervised by the University of Wales Institute Cardiff.

7. What will happen to me if I take part?

The study will last approximately 9 months. There will be two questionnaires to fill approximately 8-12 weeks apart or when you either stop attending the unit or your treatment ends, whichever happens first. If you have difficulty completing the questionnaire but would still like to take part then the researcher will help you.

Following the first and the second questionnaire the researcher may ring you to ask if she can come and ask you a few more questions so that she has a better understanding of some of the issues discovered within the study. These interviews will also include questions about your experiences of the service you attend.

8. What are the possible disadvantages of taking part?

There are no known disadvantages to taking part. The study will not affect your care.

9. Will my taking part in this study be kept confidential?

The information you give is strictly confidential and is only seen by the researcher. The people involved in delivering your care do not have access to the information. All information which is collected about you during the course of the research will be kept strictly confidential. Any information will have your name and address removed so that you cannot be recognised by it.

10. What are the possible benefits of taking part?

The information we get from this study may help us to decide the differences between the services when caring and helping service users who have both health and social care needs in the future.

11. What if I'm unhappy with the study?

Appendix 9: Study Questionnaire and Participant leaflet

If at any stage you are unhappy about the study then you should contact the researcher or her supervisor with your complaint. Furthermore, if you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service and social services complaints mechanisms may be available to you.

12. What will happen to the results of the research study?
The results of the study are likely to be published during early 2007. A copy of the report will be available on request from the researcher or from your service manager. You will not be identified in any report or publication.

13. Who is organising and funding the research?
[name] Healthcare NHS Trust and the University of Glamorgan have both funded the study as part of the researcher's degree project.

Contact for further information

Carolyn Wallace, Senior Lecturer, School of Care Sciences, University of Glamorgan, Pontypridd, CF 37 1DL. Tel: 01443 483178

APPENDIX 10: A reference tool/scale grid for practitioners

Inclusion criteria: Adult population, Function, Satisfaction, health and wellbeing, quality of life, social support, rehabilitation, suitable for use with people living in the community, chronic disease
Exclusion criteria: Mental Health, Paediatrics, LD, palliative care

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
1	**Community Integration Questionnaire**	To assess the social role limitations and community interactions using self report; Person with acquired brain injury and traumatic brain injury (prospective study- 2 groups i.e 1 year and 1-5 years post injury). To assess home social and productive activities.	Adequate test re-test reliability and internal consistency	-	Time to complete measure: It consists of 15 items relating to home integration, social integration and productive activity. Scoring: A total score is gained from through totalling the score from individual items. Range from 0 (poor integration) to 29 (high integration). A further three sub scores can be yielded (home, social integration and productivity Self administered tool. Poor definition of community	Training: Equipment: Cost:	Willar, Ottenbacher & Coad (1994) Seale et al, 2002 Minnes et al, 2003 Paniak et al, 1999 Doninger et al, 2003

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					integration weakens results.		
2	**Coopersmith Self –Esteem Inventory**	Measures individual attitude towards self in more than one context. Adult use from 16 years onwards.	acceptable	acceptable	Time to complete: 15 minutes approx 58 questions (like me/unlike me)	Training: None Equipment: Paper Cost By permission (1-500) $100-$300	Ryden, 1978; Blascovich & Tomaka, 1991
3	**Carolina Self Regulation Inventory**	Measures self regulation strategies that individuals use to help themselves recover from illness.	-	-	-	-	Pesut & Massey et al, 2007
4	**Assimilation, Integration, Marginalisation, Segregation (AIMS) Interview**	A new research and outcome measure of community integration (defined as acculturation) used with people who have moderate to mild developmental disabilities. Can also be used to inform service delivery by providing information regarding supports available to individuals in a number of domains.	-	Sound psychometric properties, including content, concurrent and construct validity	-	-	Minnes et al , 2002
5	**Community Integration**	To assess community	-	-	-	-	Minnes et al, 2003

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	Measure	integration					
6	**Help –Seeking Behaviour Questionnaire**	To measure help seeking behaviour	-	-	-	-	Hsu, 2005
7	**Brief Symptom inventory**	To identify self-reported clinically relevant psychological symptoms in adolescents and adults.	-	-	-	-	Derogatis, 1975
8	**Carers GHQ-28**	To measure carer mood	-	-	-	-	Smith et al, 2004
9	**Family Impact Questionnaire**	To measure care burden	-	-	-	-	Forster et al, 1999
10	**Family Inventory of Life Events (FILE)**	To record the normal and abnormal life events which contribute to family stress..	-	-	-	-	Artinian, 1988 ; Gardner et al, 2008
11	**Spouse Stressor Scale (SSS)**	To identify common stressors identified by partners/spouse. Used in cardiac care and rehabilitation post surgery	-	-	-	-	Artinian, 1988; Collins et al, 1996
12	**Personal Resource Questionnaire, Part 11 of Brandt and Weinert**	To measure social support					
13	**Impact on Participation and**	The IPAQ addresses autonomy and	Good test-retest	Convergent validity	Responsiveness requires further	Training: Equipment:	Cardol et al, 2001

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	Autonomy Questionnaire (IPAQ)	participation in 5 domains, autonomy indoors, family role, autonomy outdoors, social relations and work and educational opportunities. For use with peope who have chronic disorders	reliability, intraclass correlation coefficients ranged between 0.83 and 0.91	supported by correlations between 4 domains of the LHS (London Handicap Scale) and IPAQ. Discriminant validity demonstrated by low correlations between the two.	study. Self administered tool	Cost:	
14	**Norbeck Social support Questionnaire**	three types of social support i.e., affect, affirmation and aid; to measure multiple dimensions of perceived social/network support	Yes (see Norbeck, 1982)	Yes (see Norbeck, 1982)	Time to complete measure: 10 minutes (range 5-10 minutes) Short nine item, self administered questionnaire. There are three main variables, each of which has three subscales-total function (subscales:affect, affirmation and aid), total network (subscales:	Training:none Equipment: none Cost:$20 for pack which includes permission slip for use	Gigliotti, 2002 Norbeck, 1982

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					number in network, duration of relationships and frequency of contact) and total loss (subscales: recent losses of network members, numbers of losses and amount of support lost)		
15	**Norbeck Technique**	To assess network size	-	-	-	-	Zurakowski, 1990
16	**Saranson's Social Support Questionnaire**	Social Support sources and extension of the network	high level of internal consistency and an acceptable level of test-retest reliability;statistical relationship between social support indexes and variables related to work, pregnancy and income		Time to complete measure:	Training: Equipment: Cost:	Matsukura et al, 2002

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
			(Matsukura et al, 2002)				
17	**Problem Solving Inventory**	Social problem solving self appraisal	-	-	-	-	Rath, 2000
18	**Personal Problem –Solving System**	Social Problem Solving Performance	-	-	-	-	Rath, 2000
19	**Social Support Questionnaire for Transactions (SSQT) and for satisfaction (SSQS)**	SSQT (Social Support questionnaire for Transactions) measures the number of supportive interactions Perceived availability & satisfaction with social support is measured by the SSQS (Social Support Questionnaire for Satisfaction with Supportive Transactions); adult population; two part must be used together.	Yes		Time to complete measure: SSQ is 27 items and the SSQS is the short form when there is only a short time available to complete it. Each item is scored for the number of people listed and then for satisfaction. Two key scores are computed and leads to an average number of people and an average level of satisfaction. SSQT has good psychometric properties (Cronbach's Alpha for emotional support	Training: computer training Equipment: computer and software Cost:	Doeglas et al, 1996;

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					scale was 0.80 or more and for the instrumental support subscales around 0.60. Social Support consists of two measures that of supportive transactions and the perception of being supported or the satisfaction of the support provided. Compared to supportive interactions, support satisfaction was more relevant in explaining health related quality of life measures.		
20	**Brief Assessment of Social Engagement (BASE)**	To measure actual and symbolic participation in social settings for older people.	-	-	-	-	Bennett, 2002
21	**UCLA Loneliness Scale**	'To examine the degree to which respondent's social relationships provide	-	-	-	-	Cutrona & Russell, 1987

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		various dimensions of social support.'					
22	**Sheltered Care Environment Scale**			Strong evidence of construct validity of conflict, resident influence and self exploration; not for cohesion, independence and physical comfort	7 sub-scales	-	Smith & Whitbourne, 1990; Spinn, 1993
23	**Social Network Questionnaire (SNQ)**	To assess social relationships			Self administered		Pitula & Daugherty, 1995
24	**Care Giver Strain Index**	To identify strain within the informal care giver	-	-	-	-	Robinson, 1983
25	**Return to Work Scale (RTW)**	Patients with severe traumatic brain injury			Compared with Functional Assessment Measure (FAM)		Gurka et al, 1999
26	**Aberdeen Back Pain scale**						
27	**AIMS 1 & 2 (The Arthritis Impact Measurement Scales 1 & 2)**	Partly adapted from Katz's Index of Activities of Daily Living, the RAND	Yes Sensitive to change and suitable for	Yes AIMS1 extensively tested	Time to complete measure: 15-20 minutes Questions only	Training: Equipment: Cost: :	Hagen et al, 1999

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	(AIMS 2 is the shorter version)	and BUSH Scales. To assess patient outcomes in arthritis and other chronic diseases.	community use AIMS1 extensively tested AIMS2 internal consistency coefficients in RA were 0.72-0.91 OA group 0.74-0.96. test-retest reliability at 2 weeks was 0.78-0.94	AIMS 2 satisfactory with initial tests	relate to negative health. Self-administered. Used in USA, less in Europe and UK. AIMS1 has 45 multiple choice questions with nine subscales. It assesses 9 dimensions of health and functional ability (mobility, physical activity, ADLs, dexterity, household activities, pain, social activity, depression and anxiety. Another 19 items cover general health, health perceptions and demographic details. AIMS2 has 78 items, additional sections include arm function, work and social		

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					support, in addition to satisfaction with function, problems of arthritis and self designation of priority areas for improvement. A 'normalisation procedure converts scores into the range 0-10 (0= good health, 10 poor health)		
28	**Assessment of living skills and Resources (ALSAR)**	Determine 'risk' when performing instrumental ADLs through consideration of client skills and resources; Older people.			Time to complete measure: 11 skill areas (3-5 questions related to each one) are measured across two domains, skills and resources. Two separate three point scales are used to measure the two areas after which a combined score provides a task risk score.	Training: Equipment: Cost: :	Williams et al (1991)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
29	**Barthel Index (BI)**	To measure basic daily living skills in persons with chronic disability. For in-patient/ institutionalized older people in relation to amount of nursing care required; adult rehabilitation; Measures what patient actually does and not what patient is capable of doing.	Alpha reliability coefficients 0.95-0.97 (Sherwood et al, 1977); Inter-rater reliability r=0.95-1.00 & test-retest 0.89 with severely disabled adults	Good correlation (0.65)between scales (PULSES Scale) ; good predictive validity, length of stay and mortality; sensitive to recovery	Time to complete measure: 5 minutes Acceptable to staff; widely used. Assesses 10 items/activities of self care and mobility (i.e feeding, moving from wheelchair to bed and return. The BI gives two sub-totals of self care and mobility scores and one combined score, ranging from 0-100. Does not consider mental health or social wellbeing. Not a comprehensive measure of functioning (omits domestic, social or other role function), less suitable for community use and has been reported as	Training: none Equipment: none Cost: :none Full questionnaire available on wards (also in file)	Mahoney & Barthel (1965); Wellwood et al, 1995; Wilkinson et al,1997

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					insensitive to clinical change in patients attending day hospital. May be location sensitive. FIM/FAM now replaces this tool When compared with the OPCS (Wellwood et al, 1995) it was seen as still having a useful role in stroke rehabilitation when used as a checklist for rehab goals set by clinicians, as a predictor of long term outcome and as an overall measurement of disability. Though its floor and ceiling effects may lead to an underestimation of patient's carers' problems in up to a third of patients. As a standard		

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					outcome measurement it is still justified for long ternm follow up and may be a proxy for different outcome measures intended for the assessment of other domains.		
30	**Craig handicap assessment and reporting technique (CHART) revised**	Measures the extent of handicap/participatio n by examining deviation from roles performed by person without disability or impairment: Adults with spinal or brain injury.			32 items in 6 dimensions of handicap: orientation, physical independence, mobility ,occupation, social interaction and economic self sufficiency. Scoring: clinican interviews client, Each item then gives a numeric score using a weighted system incorporating time. The scores within the category are then manipulated to	Training: Equipment: Cost: :	Whiteneck et al (1992) Zhang et al, 2002

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					give a score out of 100. CHART and CIQ provide ratings that are similar in many areas. Correlation between CHART DRS and CIQ ranged from 0.021-0.671 (P<0.1)		
31	**Camberwell Assessment for the Needs of the Elderly (CANE)**	Comprehensive multi-agency needs assessment tool for older people. It defines which needs are not met and can be used to identify services and interventions required in a variety of settings including primary care, mental health services and care homes.	Very good	Very good	Qualified health and/or social care professional as an initial assessment, as part of CPA, as an outcome measure, for evaluation of services and for research. 24 areas of need covering psychological, physical, and social functioning and two areas for carer's needs. It can also identify a need for more detailed	Detailed manual available. Widely used in UK and internationally. Available from Dr Martin Orrell.	Secker et al, 2001; DOH, 2002

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					assessments in specific areas. It includes ratings for staff, user, and carer views. The older person can therefore have their needs rated separately and can express their level of satisfaction with services received. It is intended to model good clinical practice and the ratings are based on expert professional assessment.		
32	**Canadian Occupational Performance Measure (COPM)** **COPM-P (Performance subscale)** **COPM-S (Satisfaction subscale)**	To measure client self perception of occupational performance in the areas of self care; All population			Time to complete measure: dependant on client and number of problems Administered through a semi-structured interview process by a therapist in a five step process. The client drives	Training: computing Equipment: computer and software Cost: : Available: Torfaen CRT	Law et al, 1991 Trombly et al, 2002;

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					the process and the content by identifying significant issues in daily activities which are causing difficulty. Scoring system: Using a 1-10 likert scale, the client rates the importance of activities, their importance and their satisfaction with their performance. Total scores are computed for client performance and satisfaction.		
33	**Comorbidity Symptom Scale**	A scale to quantify the presence and severity of symptoms arising from comorbid diseases in older people	Test re-test correlation coefficient for the total instrument score was r=0.87 (P<.001)		A simple interviewer-administered tool for use in older people. Provides an objective measure of the presence of comorbid disease and the patient's	Training: Equipment: Cost: Available: Dept of Geriatric Medicine, University of Newcastle, Sunderland	Crabtree et al, 2000

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					perception of severity of associated symptoms.	Royal Hospital, UK.	
34	**Disability Rating Scale**	Rehabilitation-traumatic brain injury.	Reliable and useful tool for retrospective and prospective assessments of rehb outcomes.		Provides an efficient way of measuring long – term recovery when resources are limited. Is more sensitive to change than FIM and expansion of the DRS function and Employability Items might provide greater sensitivity and detail. Can help guide post acute rehabilitation planning within state or regional head injury programmes when used with FIL.		Sander et al, 2001 Hammond et al, 2001 Schatz et al, 2002
35	**Easycare**	To measure health and functional status	Able to discriminate between populations of older people		Supports locality planning through measuring population needs	Training: Equipment: Cost: Available	University of Sheffield, 2009

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
			when used as part of routine practice				
36	**Fullerton Functional Fitness Test (FFT) battery**	To assess functional status i.e mobility, muscle strength, aerobic endurance, agility and flexibility. For use within community –dwelling older adults. The battery includes Floor sit and reach, 8ft up and go, arm curl, 30-s chair stand, 2 min step and 9 min walk.	High Test re-test reliability; high Intraclass correlation coefficients	Construct validity analysis revealed that 5 out of 7 items discriminated between physically active and sedentary groups	7 item.	Training: Equipment: Cost: Available	Miotto et al, 1999
37	**Functional Independence Measure (FIM)**	To measure disability in terms of burden of care for rehabilitation inpatients; Adult population. Progression from The Barthel Index, neglects domestic activities			18 items grouped into six categories of , self care, transfers, sphincter control, communication, locomotion and social cognition. Scoring system: An ordinal rating system ranging from7-1 is used a total FIM score is given.	Training: Equipment: Cost: Available (Mardy Park, OT dept.)	Guide from the Uniform Data Set for Medical Rehabilitation (1993)
38	**Functional Assessment**						Gurka et al, 1999

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	Measure (FAM)						
39	**Functional Assessment of Care Enviroment (FACE)**	The core assessment and outcome package for older people: Supports contact , overview and comprehensive assessment Ensures accurate holistic assessment of health and social care needs Engages service users and their carers Supports risk assessment and risk management Measures health, social and risk outcomes Provides information for benchmarking of both individuals and populations			For front line practitioners & professional use. Completed as a joint assessment between professional and service user.		Fawcett, 2007
40	**Functional Independence Level (FIL)**	A measure suitable for retrospective analysis of qualitative brain injury outcome data	Inter-rater reliability coefficients for FIL were highly significant.		Compared with DRS		Schatz et al, 2002

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
			Reliable and useful tool for retrospective and prospective assessments of rehabilitation outcomes				
41	**Functional Status Questionnaire (FSQ)**						Jette et al, 1986
42	**Functional Status Index**						Oh & Feldt (2000)
43	**Frenchay Activities Index**	To measure disability and handicap following a stroke.	-	-	-	Training: None Equipment: None Cost: : Nil	The Chartered Society of Physiotherapy, 2009
44	**Goal Attainment Scaling (GAS)**	An approach to evaluating program effectiveness, investigates whether individual patient goals developed at admission are met at the time of discharge. All Population			Assign weights to each of the goals identified, achieved by consensus between client therapist, family and others. Weighting reflects prioritizing or ranking, if four goals are identified then the Most important is +4 and the least	Training: Equipment: Cost: :	Ottenbacher & Cusick (1990)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					is +1. Determine this at the goal planning stage not at the evaluation stage or it introduces systematic bias or error. A formula to determine outcome is detailed in the reference.		
45	**Gompertz's Modified Barthel Index**	A postal version of the Barthel Index	-	-	-	-	Bowling, 2001
46	**HAQ- the Stanford Arthritis Center Health Assessment Questionnaire**	Patients value systems in relation to functional ability- Arthritis	-	-	-	-	Stanford University, 2003
47	**Index of Daily Living**	To describe for clinical purposes the states of older and chronically ill patients.	Little testing; Inter-rater reliability- discrepancies between raaters in one of 20 observations; coefficient scalability 0.74-0.88	Little evidence Weakly with mobility scale (0.5) and house confinemen t scale (0.39) Predictive long term course and	Three point scale of independence for each activity. The score is then summarized on an eight point scale. Popular tool although information derived is limited due to its age and other more	Completed by a therapist or other observer	Katz & Akpom (1976)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
				social adaptation of patients with a number of conditions (inc. strokes and fractures) also predicts mortality.	comprehensive tools available (AIMS2).		
48	**Human Activity Profile (HAP)**	To measure a person's current capability to perform very easy and very strenuous physical tasks. Used with people over the age of 74 years old in relation to the positive influence of exercise on function.			94 questions in total. The HAP allows calculation of a maximum activity score (MAS) which gives an estimate of a subjects highest level of energy expenditure and a calculation of an adjusted activity score (AAS) which is an estimate of the subjects highest level of energy expenditure (a measure of usual daily activities).	Completed by therapist	Davidson & Morton, 2007

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
49	**Kurtzke Scales – Expanded Disability Status Scale (EDSS) and Functional Systems (FS)**	Disability Scales for Multiple Sclerosis	EDSS-Inter rater reproducibility is variable (ICC = 0.62-0.94). FS intra rater but not interrater reproducibility is adequate for comparison studies.	EDSS-Convergent and discriminant validity is supported. Ability to distinguish between individuals in terms of disability and responsiveness is poor. FS	EDSS is an acceptable measure but demonstrates limited variability. FS does not satisfy the criteria as an eight, 7 or six item summed rating scale. The lack of psychometric input into their (both scales) development has limited their usefulness as an outcome measure for Multiple Sclerosis.	-	Hobart et al,2000
50	**Kenny ADL Index**	-	-	-	-	-	Forster et al, 1999
51	**Karnofsky Performance index**	To determine dependence and physical performance. Lung cancer					Mor et al, 1983
52	**Katz ADL**						Forster et al, 1999
53	**London Handicap Scale (LHS)**	To enable an individual's health state to be described in terms of disadvantage in six main areas: Adults	Yes	Yes Also cross cultural validity (Lo et al, 2001) older	Six items Mobility, physical independence, work and leisure, social integration, orientation,		Harwood et al, 1994 ; Jenkinson et al, 2000

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		with physical or neurological impairment.		groups giving better scores than younger groups. Coefficient reliability for the general population 0.84.	economic self sufficiency. Self administered six point scale for each item. The concept of handicap applies across cultures although there were significant differences in perception of certain handicap scenarios by different population subgroups.		
54	**Medicare Current Beneficiary Survey**	A continuous survey of a nationally represented sample older people, people with disability and those people who live in medicare institutions (USA).	-	-	-	-	US Department of Health & Human Services, 2005
55	**Motor Club Assessment**	-	-	-	-	-	Forster et al, 1999
56	**Nottingham Extended Activities of Daily Living Questionnaire**	Total Hip Replacement					Harwood & Ebrahim, 2002
57	**Minimum Data Set**	Provides the health			Comprises of a	-	Landi et al, 2000

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	for Home Care (MDS Home Care)	or social care assessor with minimum information required for developing an appropriate care plan for an older person seeking treatment or support			screener and a full version. It includes triggers to indicate when a professional person should be involved. Provides valid and reliable data for monitoring outcomes, quality of care and resource use case mix. The patient's priorities and preferences in addition to need is discussed with them.		
58	**Nottingham Leisure Questionnaire**	Nottingham Stroke Register in a multi centre rehab trial	Tested at 6 months and 12 months with acceptable test retest reliability	yes	Shortened to a Postal self administration from 37 to 30 items and from 5 to 3 categories		Drummond et al, 2001
59	**Northwick Park ADL**	-	-	-	-	-	Forster et al, 1999
60	**Minimum Data Set- Resident Assessment Instrument**	The MDS/RAI provides systematic assessment of key domains of need for older people in care homes and guides			Designed for use by qualified nurses and care staff under supervision, with advice being	-	Dellefield, 2007

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		staff towards appropriate curses of action to plan individual care. It is for use in residential and nursing homes as a comprehensive assessment on admission and review.			obtained where necessary from outside specialists. It provides information to monitor outcomes, quality of care and resource utilisation. This approach to assessment and care planning is designed to enable both older person and care staff to discuss the assessment process and individual needs together, express preferences and priorities together.		
61	**OARS (The older American's Resources and Services Schedule)**	To measure the level of functioning and need for services of older people. Aged 55 years +; Community or institutional samples	Both OARS and FAI have been well tested. Interclass correlations range from 0.66 for physical health	Both OARS and FAI are well tested. Spearman correlation for economic and mental health	Time to complete measure: 45-60 minutes Multi-dimensional functional assessment questionnaire Measures five dimensions of	Training: 2 days interviewer training Equipment: Cost: Strictly copyright and permission	Fillenbaum, 1978

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
			to 0.87 for self-care. Test re-test reliability gave 0.47 and 1.00 , conducted 12 months apart and 0.71-0.82 at 5 weeks apart. Coefficients for life satisfaction and mental health were 0.32-0.42	items were 0.67 and 0.68, 0.82 for physical health and 0.89 for self care ability.	personal functioning, including mental impairment Shorter version available FAI (Functional assessment Inventory): 35 minutes to complete; Contains the functional measures but not the service use items. Contains two independent sections Part A functional assessment and Part B service assessment. Total number of items 120. Scoring- various ways of summing up. However, a classification which maintains distinctions between areas is preferable.	must be sought.	

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
62	**Office of Population Censuses and Surveys (OPCS) disability instrument**	To provide a comprehensive measure of disability for use in the 1985 survey of disability among adults.			May be found to be a more useful outcome measurement tool than Barthel due to its comprehensive nature.		Wellwood et al, 1995
63	**Oxford Hip Score (OHS)**	For assessment of outcome which is often used after total hip replacement	Particularly sensitive to improvements after RHR.				Wylde et al, 2005
64	**Patient Generated Index**	To measure gap between expectation and reality	Test re-test adequate More responsive to change		Self administered and interviewer administered available		Ruta et al, 1994
65	**Problem Checklist (PCL)**	To assess mild traumatic brain injury symptoms (MTBI)	Sensitive measure of MTBI				Paniak et al,1999
66	**Physical Performance Test (PPT)**	To test for physical functional capactiy	-	-	-	-	Rozzini et al, 1993
67	**The Royal College of Nursing Assessment Tool for Older People**	Designed to be used as part of an overall assessment					RCN, 2004
68	**Roland Disability Questionnaire (RDQ)**	To measure low back pain rehabilitation			Based on the generic Sickness Impact Profile. More sensitive than the Euroqol		Torenbeek et al, 2001

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					and the Aberdeen Back Pain Scale in study measuring low back pain (Garratt et al, 2001).		
69	**Visual Analogue Scale**	To measure low back pain rehabilitation					Torenbeek et al, 2001
70	**Oswestry Pain Disability Questionnaire**	To measure low back pain rehabilitation					Torenbeek et al, 2001
71	**Rivermead Mobility Index**	Stroke patients	Yes with stroke patients	Yes with stroke patients	Need good knowledge of speed		Collen et al, 1991
72	**Reintegration to Normal Living Index (RNL)**	Assess global functioning through examination of client's perception and objective indicators of physical, social and psychological performance: Adults, originally developed for clients with chronic disease.			Time to complete measure: 11 items covering mobility, self care, family roles and personal relationships, presentation of self, coping skills, housework, recreation and social activities. Scoring system: 10 points visual analogue for each item, this then is added to give a total score which is converted into a	Training: Equipment: Cost:	Wood-Dauphinee et al (1988)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					number out of 100 for ease of interpretation.		
73	**Sheffield ''Rainbow Assessment''**	A comprehensive screening & assessment tool, intended for use by qualified nurses, occupational therapists, physiotherapists and speech and language therapists at the point of entry to rehabilitation services, either within primary or secondary care settings. Although developed for rehab settings it can be used for assessing older people's needs generally.			Comprises of two sections: a screening section and more detailed assessment of particular needs and issues. The screening section provides an indication of when detailed assessment is required. Designed for use by qualified health care professionals, other agencies may feel that competent and experienced professionals are able to use the tool.		Stevenson & Spencer, 2002
74	**St. George's Respiratory Questionnaire (SGRQ)**	Disease specific measurement scale for patient with COPD (Chronic Obstructive Pulmonary Disease).					Broyles et al , 1999

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		Vulnerable people, Self Management					
75	**Therapy Outcome Measures (TOM)**	To provide a broad measure of the outcomes of each therapy (OT, SP, PT); all population			Time to complete measure: 10-15 monutes. Requires all therapists to be together to assess & evaluate patient. 4 items (Impairment, Disability, Handicap aand wellbeing/distress for each diagnosis group. Five point Likert Type Scale, which gives a basic patient profile.	Training: To read book and have collective understanding of tool Equipment: Book with cards Cost: :£20-30 Available: BG CRT	Enderby (1997)
76	**Townsend's Disability Scale**	To survey elderly population	Requires further testing	Requires further testing	Time to complete measure: short Acceptable to older people Focuses on a narrow range of activities. Difficulty with each activity is given equal weighting (0=No difficulty whilst	Training: Equipment: Cost: :	McGee et al, 1998

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					2=unable to do so alone); overall score has a range of 0-18 (score of 1-2 = slightly affected, 7-10= appreciable disability,11-18= severe disability. Various adaptations of scale have been made.		
77	**Wisconsin Card Sorting Test**	Cognitive Problem Solving					Rath, 2000
78	**Comorbidity Symptom scale (CmSS)**	A simple scale to quantify the presence and severity of symptoms arising from comorbid diseases for older people aged 65 years and over (inpatients and outpatients- cataract surgery and geriatric day hospital).	Test retest correlation coefficient for total instrument score of r=0.87 (P<.001)		It measures activities of daily living, perceived health status, anxiety and depression. 23 item scale. It is an objective measure of the presence of comorbid disease and the patient's perception of severity of associated symptoms. Interviewer-administered tool.	Training: interviewer training- simple Equipment: Cost: : Available	Crabtree et al, 2000;
79	**Cantril Ladders**	To measure					Bearon, 1989

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	(Perceived Health Status Scale)	perceived health status					
80	**DeJong & Hughes (1982) classification system of productivity status**	-					Harker et al, 2002
81	**Duke Severity of Illness Scale (DUSOI)**	To measure (generic) severity of illness in ambulatory care. Patients with diabetes or asthma.	Test re-test reliability	Concurrent validity	Requires further evaluation.	Training increases diagnosis identification.	Eccles et al, 1997
82	**Reintegration to Normal Living Index**						Harker et al, 2002
83	**Euroqual 5D (EQ5D)**	Describing health related Quality of life; non disease specific; adult age group in western society.	It has a design fault in the wording and the range of its response scales, the thermometer is biasing. Poor sensitivity particularly when used for disease-based outcomes research. Less sensitive than OHS when used in	Construct and convergenc e adequate,	Time to complete measure: 5 minutes Generates a single index value for each health state. Contains five questions relating to physical functioning, mental health and pain, and a self-rating of health on a thermometer. Too difficult for some members of	Training: trained interviewer Equipment: Cost: unknown (BG CRT evaluation)	The EuroQol Group, 1990; Dawson et al,2001

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
			assessing outcomes of RHRs.		the public, poor response rates as survey instrument, better used at interview. Difficulties in translation process i.e conceptualisation of cross culturall concepts and the transfer of meaning across languages (Jelsma et al, 2000).		
84	**Health –Related Hardiness Scale**	To measure hardiness in individuals who have health problems	-	-	-	-	Pollock & Duffy, 1990
85	**Health Promoting Lifestyle Profile**	To measure health promoting lifestyle	-	-	-	-	Walker et al, 1987
86	**Philadelphia Geriatric Centre Morale Scale (PGCMS)**	To measure morale in older people	-	-	17 questions with yes/no answers	-	Forster et al, 1999;
87	**SF-36 (Medical Outcome Study short form health survey**	To investigate the clients behavioural functioning, perceived well-being, role disability and perceptions of health; adults	-	-	Time to complete: 36 items divided over 8 health concepts such as general health, vitality, physical functioning,	Training: Equipment: Cost: : Available (in File)	Ware & Sherbourne (1992) Paniak et al, 1999

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		Useful in evaluating musculo-skeletal injuries, mild traumatic brain injury.			mental health, physical & emotional role limitations, bodily pain and social functioning		
88	**SF-12**	A multi-purpose short-form questionnaire with 12 questions. A generic measure non specific age, treatment group or disease.		Group level reliability coefficients Obtained 0.73-0.87	Self administered. 4-week recall period. Includes physical functioning, physical role, bodily pin, general health, vitality, social functioning, role emotional and mental health		Ware et al, 2002; Hurst et al, 1998
89	**SF-8**	To investigate quality of life			Takes 5-10 minutes to complete. Measures 8 domains		Dorman et al, 1998
90	**Quality of Well-being Scale (QWBS)**	To operationalise wellness for the general health-policy model; Applied to any type of disease; based on a model that combines symptom, mobility, physical activity and social activity; it combines mortality	Reliability Coefficient 0.90; Test re-test reliability 0.93-0.98;internal consistency 0.90 The tool is reliable for making group comparisons	Enhanced by incorporating death. Correlations of -0.75 between QWBS and number of reported symptoms,	Three ordinal scales (mobility, physical and social activity). Questions are based on performance and not capacity. Scoring: functional status for each of the	Training: Large commitment to interviewer training Equipment: Cost: :	Kaplan et al, 1976

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		with estimates of quality of life. Collects information on death and prognosis and so differentiates between people with equal function but unequal health status.	(Bowling, 1997).	0.96 between QWBS and chronic health problems; and number of physician contacts in the preceeding 8 days 0.55; Has convergent validity; predictive value;valid measure of health status.	scales is acquired from the respondent. Combining this information with the symptom responses and using a set of preference weights gives the QWBS score. Complex and need to be administered by trained interviewers. Useful for policy analysis and clinical research where a uni-dimensional approach is required. Not recommended if a multi-dimensional approach is required.		
91	**General Sickness Impact Profile (SIP)**	To document the effect of sickness on everyday activities and behaviour; all population; All	Test re-test reliability 0.88-0.92; internal consistency	Correlation between scales (Katz and NHISI)	Time to complete: 20-30 minutes to complete Self or interviewer administered	Training: Equipment: Cost:	Bergner et al (1981)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		population	0.81-0.97;	scored 0.64 and 0.55. Correlation with clinical status score 0.40-0.60. Less sensitive to clinical change than SF-36 and Barthel Index	interview; 15 point scale which is added up and given an overall score 136 items which describe a specific dysfunctional behaviour:12 categories and two dimensions physical and psychosocial which include sleep & rest, eating, working, home management, recreation and pastimes, ambulation, mobility, bodily care and movement and social interaction, alertness behaviour, emotional behaviour and communication. Valuable for use with assessing		

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					impact of illness on patients with chronic illness. Time consuming and tiring to complete.		
92	**Kahn Mental Status Questionnaire**	To measure mental state and psychological wellbeing			-	-	Forster et al, 1999
93	**Nottingham Health Profile**	To document a patient's perception of their health status and the effects of it on their behaviour; All Population; acceptable to older age group.	Test-retest reliability 0.45 (home life)-0.88;	Face, content and criterion validity satisfactory ; sensitive to change; correlates well with clinical measures; predicts LOS in hospital patients and progress at 3months and one year;discriminates between normal	Time to complete: short Self administered; simple to do so;Dichotomous scale (yes/no). Empirically weighted scores for 'yes' responses. Scores are presented in terms of a profile rather than an overall score. The higher the score the greater the perceived number of problems 45 items divided over 6 sub scales (physical mobility, pain, sleep,	Training: Equipment: Cost: : inexpensive	Hunt et al (1981)

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
				population and chronic illness;	emotional reactions, social isolation and energy) Provide only a shallow profile needs to be used in combination with other tools e.g a functional disability scale		
94	**Rivermead Rehabilitation Centre Life Goals Questionnaire**	To measure the individual's perception of the importance of life roles; Adult population	-	-	Time to complete: Nine items related to the importance of residential and domestic arrangements and ability to manage personal care, leisure work, hobbies and interests, contacts with friends and neighbours, family life religion and finances. Scoring system: A four point scale 0-3 (3= extreme importance). A client profile is acquired along with data on	Training: Equipment: Cost: :	Davis et al, 1992

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					individual items.		
95	**Quality of Life Index (QL-INDEX)**	A global measure of quality of life. Developed for persons with cancer or other chronic physical diseases. Adult population.	-	-	Time to complete: Consists of five items (activities of daily living, health support and outlook). Scored by therapist or by client. Each item is rated on a three point ordinal scale which is then totalled to provide a QL-INDEX totalscore.	Training: Equipment: Cost	Spitzer et al, 1981
96	**Life Satisfaction Questionnaire**	To measure client satisfaction with life as a whole (happiness); General Adult population	-	-	Nine items examining client satisfaction with family , life and friendship, financial situation, vocational situation, leisure and selfcare. Six point score ranging from 1 (very dissatisfied) to 6 (very satisfied). Provides a client profile which can be monitored over	Training: Equipment: Cost	Nelson et al, 1987; Fugel-Meyer et al, 1991

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					time.		
97	**Dartmouth COOP Charts**	A general health measure	yes retest intraclass correlations for elderly patients ranged from .78 to .98	yes	Consists of nine questions. Five response categories for each question with each response category being linked to a drawing intended to represent the health state. They cover physical functioning/fitness , feelings/emotional condition, daily activities, social activities, pain, overall health, social support and quality of life. A further question aske the patient to look at change in health	Training: Equipment: Cost	Nelson et al, 1987;McHorney et al (1992); Wasson et al, 1992
98	**Schedule for the Evaluation of Individual Quality of Life (SEIQOL)**	To measure quality of Life Trauma patients, older people, hip replacement patients			Interviewer administered with direct weighted procedure to weight respondents	Training: Equipment: Lap top computer Cost:	O'Boyle et al, 1992

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
					nominated areas.		
99	**Lancashire Quality of Life Profile**	General quality of life questionnaire which has increasingly been used for mental health patients.	-	-	-	-	Secker et al, 2001; van Nieuwenhuizen et al, 2001
100	**Verona Satisfaction with Service Scales**	-	-	-	-	-	Secker et al, 2001;
101	**Measures of Processes of Care**	Focusses on service receivers experiences of the family centredness of the service.	-	-	56 items in addition to 5 items concerning perception of level of control over service provision.	-	Wolfe et al, 2002
102	**QALY (Quality Adjusted Life Years)**	A method of valuing the benefits of health care.	-	-	-	-	Kaplan, 2004
103	**General Health Questionnaire (GHQ-30)**		-	-	-	-	Ohta et al, 1995
104	**Geriatric Quality of Life Questionnaire**	A health-related qualify of life (HRQL) questionnaire designed for the frail elderly. The GQLQ includes 25 questions focusing on activities of daily living (ADL), symptoms, and	Responsiveness coefficients ranged between 0.26-0.50	-	-	-	Guyatt et, 1993

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
		emotional function.					
105	**Sickness Impact Profile (SIP)**	-	-	-	-	-	Forster et al, 1999
106	**Satisfaction with Life Scale**	Traumatic brain injury		-	-	-	Corrigan et al, 2001
107	**Survival satisfaction Questionnaire**	-	-	-	--	-	Forster et al, 1999
108	**Psychological Distress Scale**	-	-	-	-	-	Forster et al, 1999
109	**Geriatric Depression Scale**	To measure depression in older people	-	-	15 questions with yes/no answers.	-	Forster et al, 1999,
110	**Zung Depression Index**	-	-	-	-	-	Forster et al, 1999
111	**Attitudes Towards Persons with Disabilities Scale O-Version**	-	-	-	-	Self administered tool	Snead & Davis, 2002
112	**Acceptance of Disability Scale**	-	-	-	-	Self administered tool	Snead & Davis, 2002
113	**Rand-36 Health**	-	-	-	-	Self	Snead & Davis, 2002

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	Status Inventory					administered tool	
114	**Health Related Quality of Life (HRQoL)**	-	-	-	-	-	Monninkhof, 2003
115	**Perception of Illness Severity Ladder Scale**	-	yes	yes	-	-	Artinian, 1988
116	**Strain Questionnaire (SQ)**	Stress Response Measure	yes	Yes	-	-	Artinian, 1988
117	**Role Strain Scale (RSS)**	Stress Response Measure			-		Artinian, 1988
118	**Dyadic Adjustment Scale**	Stress Response Measure	Yes	Yes	-	-	Artinian, 1988
119	**Beck Depression Inventory (BDI)**	To diagnose and assess depression	-	-	Self administered	-	Pitula & Daugherty,1995
120	**Psychological General Wellbeing Schedule**	-	-	-	-	-	Spinn, 1993
121	**International Physical Activity Questionnaire**	To measure cross national monitoring of physical activity	acceptable	acceptable	-	-	Craig et al, 2003

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
	(IPAQ)	and inactivity for 18-65 year olds					
122	**Homebound Diabetes Knowledge level Questionnaire** **Diabetes Clinical Indicator Tool**	-	-	-	Further refinement of the tool is required, especially in relation to non-insulin-dependent diabetes mellitis clients	-	Zink et al, 1996
123	**Physical Activity Questionnaire**	To measure physical activity Population group-Persons living with HIV disease	-	-	-	-	Craig et al, 2003
124	**Profile of Moods Scale**				Contains depression and anxiety subscales	-	Oh & Feldt (2000)
125	**Verbal descriptor Scale**				-	-	Oh & Feldt (2000)
126	**Demands of Illness Inventory (DOII)**	To measure personal illness demands	adequate	adequate	Self administered	-	Oakley & kane, 1999
127	**Short Portable mental Status Questionnaire by Pfeiffer**	To measure cognition	-	-	10 item short score	-	Pfeiffer, 1975
128	**McClosky-Schaar Anomia Scale**	To measure basic effect of education on disadvantaged	-	-	-	-	Moore, 1972

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
129	**Wallston's Health Locus of Control (Form C)**	To measure Locus of Control	-	-	-	-	Wallston et al, 1994
130	**Chronic Respiratory Disease Questionnaire (CRQ)**	To measure outcomes in chronic respiratory disease e.g. Asthma	Responsive measure of acute changes	Measures short term changes in dyspnoea and QOL	Changes were highly correlated with clinical outcome and with other health measures.	-	Lacasse et al, 2003;Aaron, 2002;
131	**Glasgow Coma Scale (GCS)**	To provide a simple method of monitoring and recording change in the level of consciousness of head injured patients	-	-	-	-	Gabbe et al, 2003
132	**The Team Survey**	A tool for health care development	-	-	-	-	Millward & Jeffries 2001.
133	**The RCN Nursing Older people assessment Tool**	An assessment tool to determine the need for registered nursing by older people in continuing care.	High	High	-	-	Ford & McCormack, 1999
134	**Dutch Fatigue Scale**	Based on NANDA's defining characteristics of fatigue. Used to assess Fatigue. Used with Chronic Heart Failure	Yes	Yes	Easy to use. Accurate recognition of the existence and extent of fatigue.	-	Tiesinga et al, 2001

No	Outcome measure	Appropriateness	Reliability	Validity	Acceptability	Feasability	Reference
135	**Minnesota Living with Heart Failure Questionnaire (LHFQ)**	To measure Quality of Life (QOL) in patients with chronic heart failure.	-	-	The LHFQ subscales may be less useful in QOL assessment that the total score. SF-36 better able to differentiate physical and emotional aspects of QOL in the sample of heart failure patients (Sneed et al, 2001)	-	Sneed et al, 2001)
136	**Modified Health Assessment Questionnaire (MHAQ)**	Disease specific questionnaire-Rheumatoid Arthritis.	-	-	-	-	Hagen et al, 1999

Appendix 11: Ethical approval

[name] Local Research Ethics Committee

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13 December 2004

Ms Carolyn Wallace
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Dear Ms Wallace

Full title of study: An exploration of health and social care service integration in a deprived South Wales area

REC reference no: 04/WSE05/6

The Research Ethics Committee reviewed the above application at the meeting held on 29 November 2004.

Ethical opinion

The members of the committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the research sites listed on the attached form.

Approved documents

The documents reviewed and approved at the meeting were:

Document type:	Version:	Dated:	Date received:
Application		17/11/2004	29/11/2004
Investigator CV		17/11/2004	29/11/2004

Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R & D Department for the relevant NHS care organisation.

Membership of the committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Chris Noton
Chair

Enclosures: List of names and professions of members who were present at the meeting

Mr Chris Noton	-	Chairman
Mrs Jean Matthews	-	Pharmacy Member
Mrs Sue Bell Thomas	-	Consultant Member
Mr Peter Hughes	-	Lay Member
Mrs Sally Dawson	-	Nurse Member

Appendix 12: Pilot Report

1. **Title:** Pilot Study January 2005 for 'An exploration of health and social care service integration in a deprived South Wales area'.

2. **Background:** The aim of the PhD study is to 'explore whether there is a difference between integrated health and social care day services and non-integrated health and social care day services'.

   The purpose of this pilot study was identified within the study protocol as giving the researcher an opportunity to uncover any weaknesses and strengths of the primary and secondary measurement tools only. In order to achieve this, the primary outcome measures were collated for 1 month by unit staff, in order to ensure that the framework to collect this data is in situ.
   A pilot study of the secondary outcome measures included approximately12 respondents in total from the study population (Bowling, 1997). This required explaining to the participants that the questionnaire is being tested and will be accompanied by a one-to-one interview to gather any information they have about their experiences of completing the form. It was anticipated that this would test whether the font and its size ensured that the questionnaires were easily read, gather comments on the length and content of the questionnaire (any repetition etc), uncover any typographical errors, and indicate how many participants would need assistance due to physical disability. The data was collected from 12 respondents within one of the identified study groups.

3. **Results:** As anticipated this found that the font and its size needed some adjustment to a larger size (14 rather than size 12) and that the whole question with its optional answers needed to be on the same page. Other comments gathered included a typographical error and the need to include a space for the date completed and the unit name on the front page. This pilot also gave an indication as to how many participants may have needed assistance due to physical disability. This was anticipated to be in the region of approximately 10% due to blindness and the physical effects of stroke.

   In addition to the formatting of the secondary tool, the process of collecting the data then questioned the researcher as to how this information was to be clearly stored and labelled. As a result the questionnaires from each of the study groups were stored in Lever Arch files and clearly identified as pre and post questionnaires. The identification numbers were then entered into the case study database. This Case Study Database at this stage is an Excel workbook with a sub sheet for each study group. Each study group sub sheet includes the primary information by month and the individual participant identifier with date of 1st and 2nd questionnaire. It is acknowledged that the researcher needs to undertake training in both SPSS and Nvivo packages in order to enter the information collected and analyse it in the future.

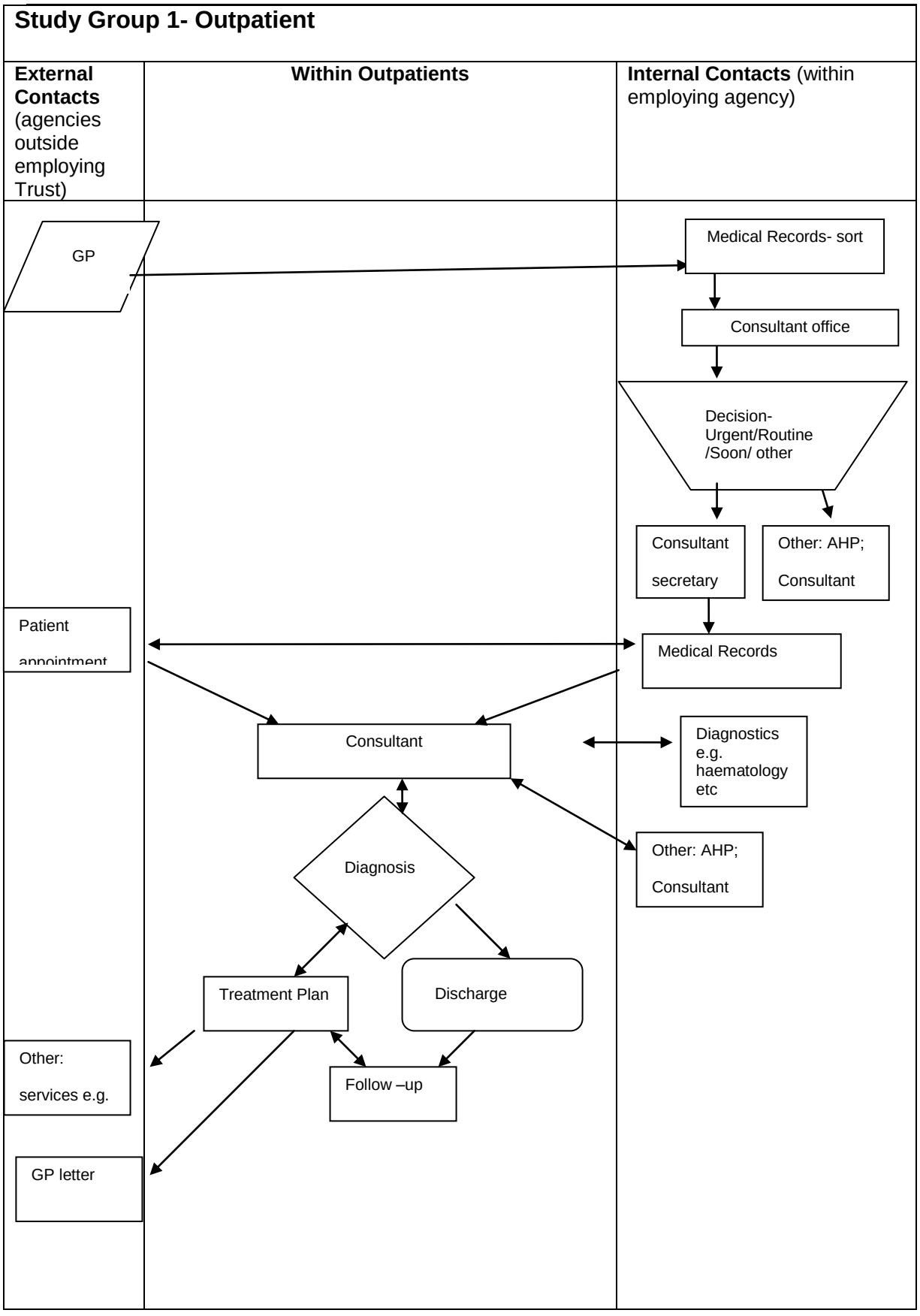
Questions as to how the information will be transferred onto such packages and how the researcher will manage to analyse all the information needs also to be answered. This will be achieved through undertaking the training at the appropriate time. Collecting these questions and learning from experiences such as the pilot need to be collated within the research diary which has not yet commenced.

4. **Conclusions:** The pilot has given the researcher an opportunity to test the ability of the study groups to collate the data and to anticipate any problems with the study tools. It has highlighted issues with regard to not only data collection but also storage and the researcher's ability to analyse the data in the future. However, the main focus at present must be the data collection and the task ahead which no doubt will take some time and some coordinating. In order to rationalize thoughts the researcher needs to develop the research diary otherwise experiences will be lost.

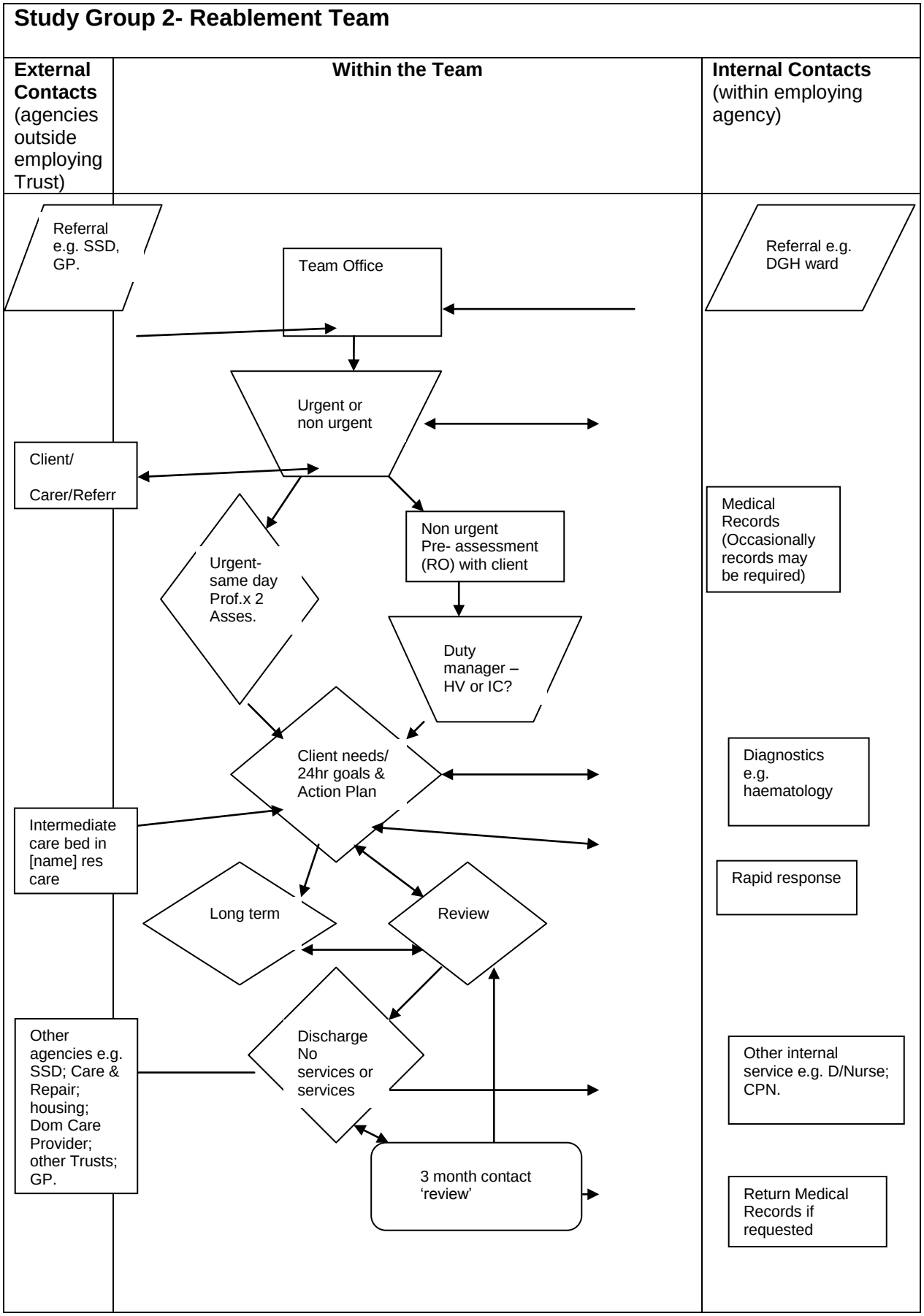
5. Recommendations:

- To alter the documentation as indicated within the pilot e.g. font to increase to size 14. Be prepared to undertake interviews and that this will take some time, which is as yet to be quantified.
- Researcher to undertake SPSS and Nvivo training at the appropriate time.
- To commence data collection and the research diary to capture the researchers experiences.

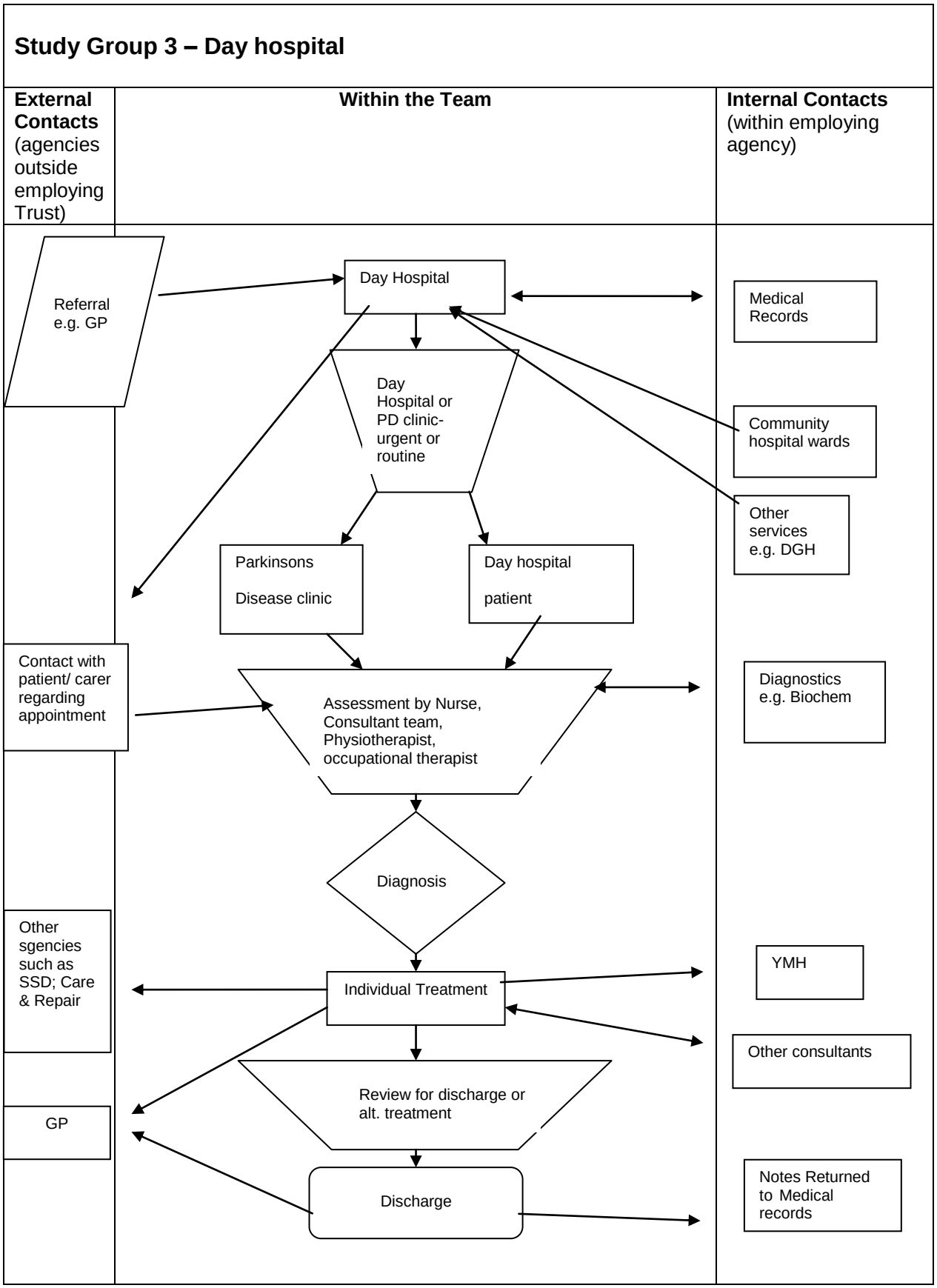
Appendix 13 – Process Flow Charts



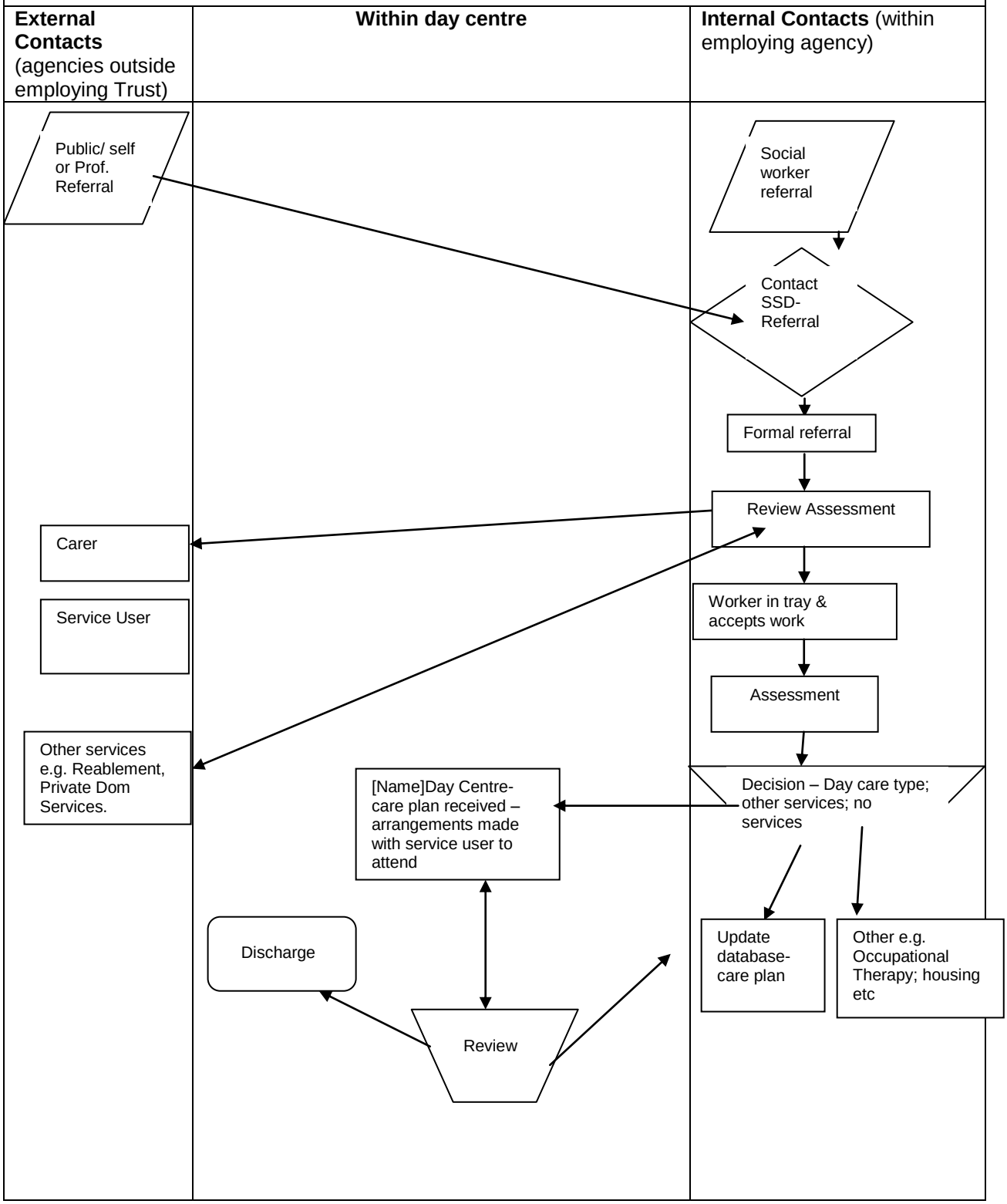
Process Flow Chart

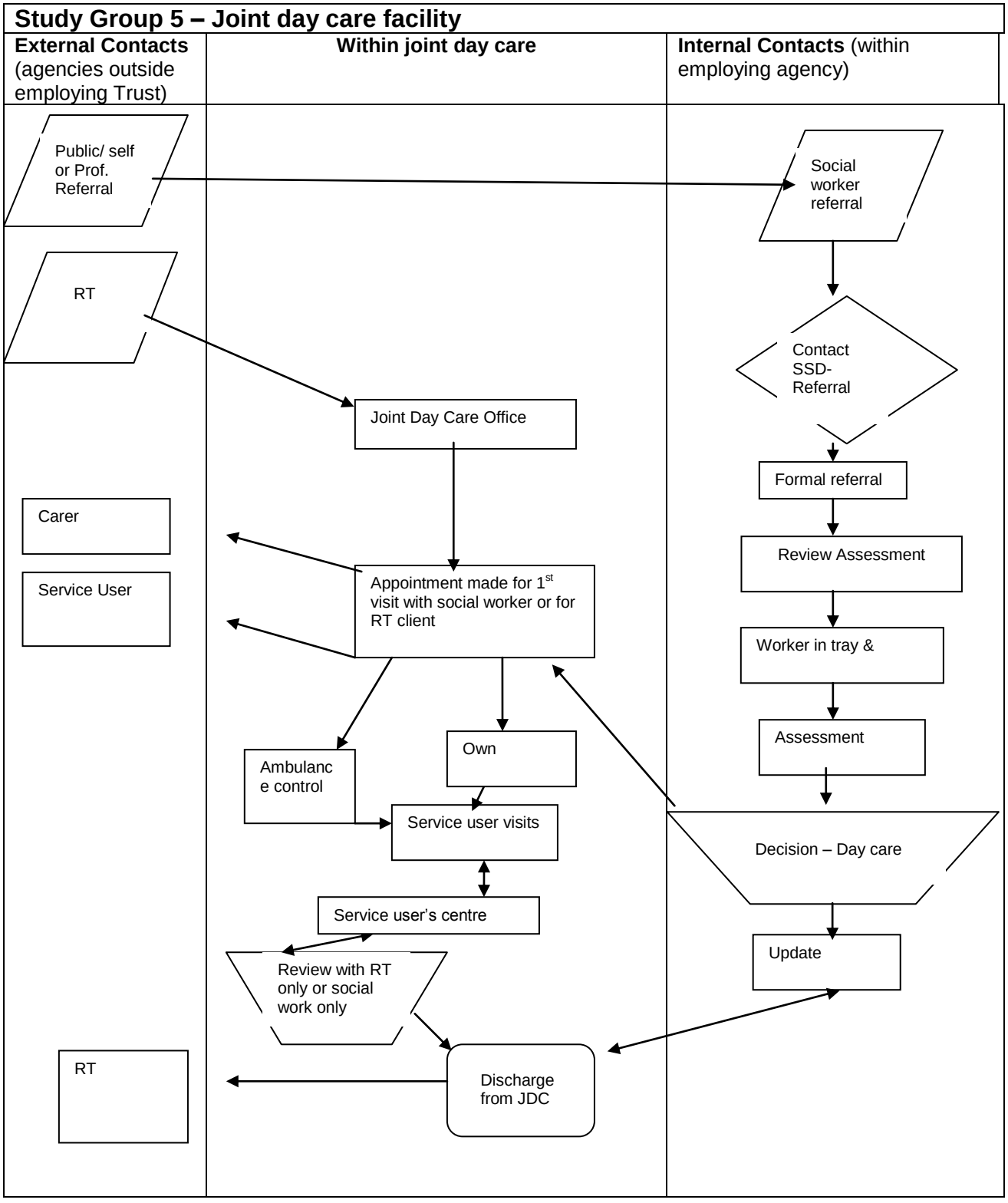


Study Group 3 – Day hospital

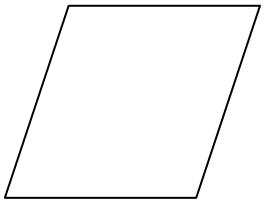


Study Group 4 – Day Centre



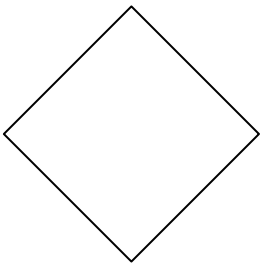

Study Group 5 – Joint day care facility
External Contacts (agencies outside employing Trust)
Within joint day care
Internal Contacts (within employing agency)
Public/ self or Prof. Referral
RT
Carer
Service User
RT
Joint Day Care Office
Appointment made for 1st visit with social worker or for RT client
Ambulanc e control
Own
Service user visits
Service user's centre
Review with RT only or social work only
Discharge from JDC
Social worker referral
Contact SSD- Referral
Formal referral
Review Assessment
Worker in tray &
Assessment
Decision – Day care
Update

Common ISO 9000 flowcharting symbols



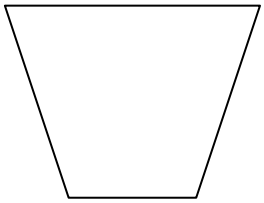
Beginning

or



Decision

Process Step



Decision choice

Appendix 14: tree nodes created in Nvivo 7.0 software

Type	Name	Memo Link	Sources	References	Created By	Created On	Modified By	Modified On
Tree Node	care coordination		0	0	CW	15/03/2009 17:04	CW	15/03/2009 17:04
Type	**Name**	**Memo Link**	**Sources**	**References**	**Created By**	**Created On**	**Modified By**	**Modified On**
Tree Node	Active service user coordination		9	25	CW	18/03/2009 21:43	CW	09/05/2009 11:46
Tree Node	carer coordination control		4	7	CW	18/03/2009 21:43	CW	18/03/2009 21:43
Tree Node	collaborative relationship between service user and carer		8	24	CW	18/03/2009 21:43	CW	09/05/2009 12:25
Tree Node	dependent service user formal coordination		8	12	CW	18/03/2009 21:43	CW	09/05/2009 11:46
Tree Node	imposed dependency		6	12	CW	18/03/2009 21:43	CW	18/03/2009 21:43
Tree Node	Passive service user		9	17	CW	18/03/2009 21:43	CW	17/06/2009 14:03
Tree Node	Proactive caring	Yes	5	15	CW	19/02/2009 13:45	CW	09/05/2009 12:25
Tree Node	proactive client		4	12	CW	19/02/2009 13:45	CW	04/04/2009 18:27
Tree Node	problem solving carer		3	22	CW	18/03/2009 21:44	CW	09/05/2009 12:25
Tree Node	checklist for integrated services		8	9	CW	19/02/2009 13:46	CW	07/05/2009 21:58
Tree Node	environment		1	2	CW	07/02/2009 18:37	CW	11/03/2009 11:50
Tree Node	The day services case		1	1	CW	29/08/2008 20:38	CW	24/02/2009 16:00

Type	Name	Memo Link	Sources	References	Created By	Created On	Modified By	Modified On
Tree Node	Choice		4	5	CW	29/08/2008 20:23	CW	04/04/2009 18:27
Tree Node	conversion process		5	26	CW	07/02/2009 18:31	CW	04/04/2009 18:27
Tree Node	RT		61	206	CW	19/02/2009 13:43	CW	09/05/2009 11:46
Tree Node	Day centre [name]		33	157	CW	19/02/2009 13:43	CW	18/03/2009 13:05
Tree Node	day hospital		45	160	CW	19/02/2009 13:43	CW	09/05/2009 12:25
Tree Node	detached care planning		1	1	CW	19/02/2009 13:43	CW	19/02/2009 13:43
Tree Node	health and social care interface	Yes	5	6	CW	19/02/2009 13:43	CW	18/03/2009 15:26
Tree Node	information sharing		4	15	CW	19/02/2009 13:44	CW	24/02/2009 16:00
Tree Node	Inputs		4	10	CW	07/02/2009 18:19	CW	04/04/2009 18:27
Tree Node	leadership		1	1	CW	19/02/2009 13:45	CW	23/02/2009 13:09
Tree Node	Levels of integration	Yes	8	12	CW	19/02/2009 13:44	CW	19/02/2009 13:44
Tree Node	outpatients		27	84	CW	19/02/2009 13:45	CW	09/05/2009 11:31
Tree Node	output		2	5	CW	07/02/2009 18:32	CW	11/03/2009 11:50
Tree Node	Role of the informal carer		4	11	CW	19/02/2009 14:57	CW	18/03/2009 15:26

Appendix 15: list of Data Sources

1. Documentation

Document Study Number	Reference
	Historical, Strategic, Background Context
13	Audit Commission (2003) A Report of the Joint Review of social services in Blaenau Gwent. National Assembly for Wales.
8	Blaenau Gwent County Borough Council (2001/2002/2003) Residential/ Respite Care Services. Business Plan. Provider Division. Social Services Department.
4	Blaenau Gwent County Borough Council (2003) Draft Action Plan in Response to Joint Review May 2003
10	Blaenau Gwent Local Health Board., Blaenau Gwent County Borough Council (no date) Draft Health social care and wellbeing strategy
14a	Blaenau Gwent County Borough Council., Blaenau Gwent Health Group (Gwent Health Authority)., Gwent Healthcare NHS Trust., Gwent Association of Voluntary Organisations (GAVO)., Voluntary & Private Sectors., Service Users & Carers., Blaenau Gwent Housing Department., (2002/2007)Blaenau Gwent draft Health and Social Care Plan.
14b	Blaenau Gwent Local health Board., Blaenau Gwent County Borough Council., (2005-2008a)Healthier Future A Partnership strategy to improve the health, social care and wellbeing of the people of Blaenau Gwent Accessed on 07/10/09 at http://www.wales.nhs.uk/sites3/Documents/280/HealthierFutureStrategy_English1.pdf
14c	Blaenau Gwent Local health Board., Blaenau Gwent County Borough Council., (2005-2008b)Healthier Future' Action Plan A Partnership strategy to improve the health, social care and wellbeing of the people of Blaenau Gwent. Accessed on 07/10/09 at http://www.wales.nhs.uk/sites3/Documents/280/HealthierFutureActionPlan2005-20081.pdf
14d	Blaenau Gwent Local Health Board., Blaenau Gwent County Borough Council., (2003)'Living in Blaenau Gwent' Consultation Summary Document. A needs assessment to inform the Health, Social Care and Well Being Strategy. Accessed on 07/10/09 at http://www.wales.nhs.uk/sites3/Documents/280/NeedsAssessment_Summary.doc
14e	Blaenau Gwent County Borough Council (Social Services Department) (2006) Living Independently in Blaenau Gwent in the 21st Century- Commissioning Strategy for Older People Age 65 Plus: 2006-2021, Ebbw Vale: Blaenau Gwent County Borough Council. Accessed on 07/10/09 at http://www.blaenau-gwent.gov.uk/CouncilAgendas/Council/COUNC0611A1/COUNC0611A1N4473/COUNC0611A1N4473c.pdf
15	Blaenau Gwent County Borough Council (May 2002) Joint Review Position Statement. Social services Department.
28	Blaenau Gwent Local Health Group., Blaenau Gwent County Borough Council., Gwent Healthcare NHS Trust (1999) Report on Service User Satisfaction Survey for Day Care Facilities for Elderly Frail within Blaenau Gwent
53	Blaenau Gwent County Borough Council. (2005-2009) Blaenau Gwent Community plan. Proud Past, bright future. Accessed on 07/10/09 at http://www.blaenau-gwent.gov.uk/1370.asp
5	Commission for Health Improvement (2001)Report of a clinical Governance review of Gwent Health Authority
24	Community Reablement Project (2001)Estates file
11	District Audit (2001) Rehabilitation in Gwent
1	Gwent Health Care NHS Trust (2003) Service guide. GHCT
7	Gwent Health Authority (1997a) Policy on discharge
9	Gwent Health Authority (1997b) Accountability framework
12	Gwent Health Authority/ Blaenau Gwent County Borough (2002-2007) Council Health and social care plan strategic intentions
18	Gwent Health Authority (1998) Improving health together. The annual report of the director of Public Health. Pontypool. Gwent Health Authority.
55	Gwent Healthcare NHS Trust (2001) Trust Fund Community Reablement Team
54	Health Inspectorate Wales (2007)Gwent Healthcare NHS Trust Review of Progress against Healthcare Standards for Wales 1 April 2006- 31March 2007. Accessed on 07/10/09 at

Document Study Number	Reference
	http://www.hiw.org.uk/Documents/477/Gwent%20Healthcare%20Trust%20Report%202006-07%20-%20for%20publication2.pdf
16	Office of National Statistics (ONS) (2001) Blaenau Gwent Census 2001. Key Statistics Summary Blaenau Gwent County Borough Council
22	Social Services Department (2002) Joint Review File
27	Unknown (no date) Development process and minutes of meetings File
Service documents	
20	Blaenau Gwent Local Health Group (no date) Joint agenda group. Social Services. Gwent HealthCare NHS Trust
23	Blaenau Gwent Health Alliance (2002) Healthy Communities Forum. Accident and Prevention Sub-Group
25	Blaenau Gwent Local Health Group (2002-2003) Whole systems project- Blaenau Gwent/Elderly Care Group. Gwent Healthcare NHS Trust. Blaenau Gwent County Borough Council.
31	Blaenau Gwent Local health Group (2002) GP practice admin group
32	Blaenau Gwent County Borough Council (2001-2003) Project leaflets File.
34	Blaenau Gwent Social Services Department (no date) Departmental Management Team Notes
37	Blaenau Gwent Social Services Department (2001-2002)Day Services Team Meetings
38	Blaenau Gwent Local Health Group., Blaenau Gwent County Borough Council., Gwent Healthcare NHS Trust (1999) Joint Day Care Project Model and business case
46	Blaenau Gwent Local Health Board (1999-2003) Joint day care steering group. Joint Day Care Project.
50	Blaenau Gwent Community Reablement Project (2001-2002)Queen's Nursing Institute File
51	Blaenau Gwent Social Services (2003-2004) Joint Day Care Unit File
47	Blaenau Gwent County Borough Council Social Services Department(1997-2000) Day Service Review & Development Plans: Establishing Luncheon Clubs. Luncheon Club Service Specification
2	Community Reablement Project (2003)Free Home Care File.
19	Community Reablement Project (no date) Equipment File.
26	Community Reablement Project (2001-2003a) Core implementation group file
29	Community Reablement Project (2001-2003b) Personnel sub group file
35	Community Reablement Team (2000-2004) Correspondence (letters and e-mails) file
36	Community Reablement Team (no date) Trust Fund File
43	Community Reablement Project (1999-2004)Evaluation sub group and evaluation report file.
44	Community Reablement Project (2001) Support worker training and competencies
52	Community Reablement Team (2005-2008) Joint documentation.
33	Gwent Health Care NHS Trust (2001) Diagnostics correspondence 2001. Joint Day Care Project.
39	Gwent Healthcare NHS Trust (1999-2001) Multi-professional group file
21	Gwent Healthcare NHS Trust (2003-2004) Blaenau Gwent, Monmouthshire & Torfaen Borough Team Briefs-Management Team Meetings
48	O'Leary, M., (1999) Day service strategy: Day Care for the Elderly 080299. Report for Chairman (Draft for a Committee Report). Blaenau Gwent Social Services
30	Social Services Department (2002-2003)Notes Manager's Briefing Meeting
3	Upton, D., (2003) Blaenau Gwent Community Reablement Service Project: Final Report. University of Wales, Cardiff
17	Wallace, C., Lane, A., (2002)Tyleri Court Day Service & Blaenau Gwent Community Reablement Project Business Plan . Blaenau Gwent Social Services. Gwent Healthcare NHS Trust. Blaenau Gwent Local Health Board.
40	Wallace, C., (2001) CRT Project Manager diary
41	Wallace, C., (2002-2004) CRT Project Manager diary
42	Wallace, C., (2002) Day Hospital Review 2002. Gwent Healthcare NHS Trust

Document Study Number	Reference
45	Unknown (2003-2004)Recreational Therapy Assistant File
49	Unknown (2001) A joint retrospective study of clients entering residential placement December 2001

2. Process Flow Maps

Process Flow Map (PF)	Name
PF1	Study Group 1 (OPD)
PF 2	Study Group 2 (RT)
PF 3	Study Group 3 (day Hospital)
PF 4	Study Group 4 (day care)
PF 5	Study Group 5 (JDC)

3. Interviews

Interview	Study Group/ Type of participants
1	Study Group 2/ service user(RT)
2	Study Group 2/service user(RT)
3	Study Group 2/staff(RT)
4	Study Group 2/staff(RT)
5	Study Group 2/staff(RT)
6	Study Group 2/carer(RT)
7	Study Group 4/carer(day care)
8	Study Group 4/service user(day care)
9	Study Group 4/service user(day care)
10	Study Group 4/staff(day care)
11	Study Group 4/service user(day care)
12	Study Group 5/ staff(JDC)
13	Study Group 5/ service user & carer(JDC)
14	Study Group 5/service user(JDC)
15	Study Group 5/service user(JDC)
16	Study Group 5/service user & carer(JDC)
17	Study Group 5/ staff(JDC)
18	Study Group 1/service user(OP)
19	Study Group 1/service user(OP)
20	Study Group 1/ carers(OP)
21	Study Group 3/service user(day Hospital)
22	Study Group 3/service user/carer(day Hospital)

23	Study Group 3/staff (day Hospital)
24	Study Group 3/ service user & carer (day Hospital)
25	Study Group 1/ staff (OP)

4. Observations (Obs.)

Number	Study group
1	Study Group 3 (day Hospital)
2	Study Group 5 (JDC)
3	Study Group 1(OP)
4	Study Group 4 & 5 (day care & JDC)
5	Study Group 4 (day care)
6	Study Group 4 (day care)
7	Study group 5 (JDC)
8	Study Group 2 & 4 (RT & day care)
9	Study Group 2 & 3 (RT & day Hospital)

5. Research Diary

Dates
18/08/05
23/08/05
21/10/05
09/11/05
26/01/06
10/02/06
13/02/06
17/02/06
25/02/06
01/03/06
10/03/06
16/03/06
23/03/06
19/04/06
03/07/06
18/08/06
28/08/06
09/09/06
19/09/06
21/10/06
01/11/06
15/11/06

6. Letters of explanation attached to survey questionnaire

Date	Survey identity code	Study group
24/08/05	BE0209	Study Group 2
15/12/2005	GB310822	Study Group 2
20/02/06	DA291231	Study Group 3

Appendix 16: Chronology of events

Date	*Event/ key documents*	*Recommendation/Result of event*	*Source of evidence (Doc No.)*
1996	*Joint review of day care provision by Local Authority Social Services Dept and [name] NHS Trust*	*Recommendation for pilot project to consider and assess the value of joint day care. Due to an overlap of services provision and an identified group of people whose needs were not being met. Proposal for a Pilot Joint Health and Social Services Day care Facility (1997).*	*17;28;47;48;39*
1998	*Local Health Group Commissioning Objectives. 'Improving health Together'*	*Annual report of [name] Health Authority Director of Public Health which was designed to support local commissioning.*	*18;38*
1999	*Appointment of Joint Day Care Development Officer (6 month project)*	*Business case with model and operational policy Service User Satisfaction Survey for Day Care Facilities for Elderly Frail. Recommended the development of a pilot project to test the model identified in 1996.*	*17;28; 27;38; 48*
2000	*Funding acquired (by Local Health Group) for pilot (18 months). New Flexibilities form agreed by NAfW.*	*Appointment of joint (health and social care) Project Manager agreed.*	*10;17;39*
2001	*New Flexibilities form agreed by NAfW.* *Pilot commenced August 2001.* *Queen's Nursing Institute award for Innovative and Creative Practice (project manager)* *District Audit (2001) 'Rehabilitation services for older people in [name]' criticism of service provision.*	*Appointment of joint (health and social care) Project Manager and the team.* *National recognition for the RT Project. £5000 for the evaluation and to develop home assessment through hand held PCs.* *Recommendation: A joint rehabilitation strategy for [name].*	*39* *11;39* *35;50* *11;42*

Date	Event/ key documents	Recommendation/Result of event	Source of evidence (Doc No.)
2002	*Day Hospital Review ([name] Healthcare NHS Trust) (Project Manager)* *Announcement and demolition of [name] day centre.*	*Recommendation of whole systems approach to service integration across health and social care day services by locality. Services should be 7 days per week.* *Agreed integration of day hospital and [name] Day Centre to form the JDC. RT and JDC moved to [name] community hospital 25/11/02.*	*21; 30;42; 35* *21;26;30;35;37*
2003	*RT evaluation UWIC* *Integration of [name] day hospital and [name] day centre to the Joint Day Care Service. Both JDC and RT based at [name] Community Hospital.* *Highly Commended from the Community Hospital Association in 2003 (project manager)* *RT permanent status* *Joint Review & Action plan in response to Joint Review*	*Suggested 'a positive impact upon health and wellbeing of individuals admitted to the service'; 'evidence suggests that the service has a more beneficial impact than either the day centre or the day hospital'.* *JDC recognised as a future model to replace Day hospital and day centre provision.* *Staff have permanent contracts as opposed to secondment or temporary contracts.* *'Developing joint services with Health that focus on prevention and rehabilitation are a priority' (Doc. 13, p9). 'Increase the capacity of the reablement service by retraining home care staff'(Doc. 4, p6)*	*21;35;37;43;* *21;25;10;51* *21;37;51* *21; 35;37;51* *4;13;15; 51;37*

Date	***Event/ key documents***	***Recommendation/Result of event***	***Source of evidence (Doc No.)***
2004	*JDC and RT move to [name] Leisure Centre.* *RT & JDC Project manager*	*JDC create relationships with Leisure centre staff., management of RT moves from LHB to NHS trust.* *Management of JDC and RT move to employing agencies. Project manager replaced by operational management arrangement.*	*35; 37; 51* *Doc.41*
2005	*RT Move to [another name] Hospital August 2005.*	*Co-location of RT and JDC ended*	*Int. 12*

Appendix 17 – Meta Matrix – understanding the whole – the results

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
How were integrated services different?	• Group age below av. Life exp. Of the total population. (SF-12v2/LHS questionnaire)	• Group age below av. Life exp. Of the total population. (SF-12v2/LHS questionnaire)	• Group age below av. Life exp. Of the total population. (SF-12v2/LHS questionnaire)	• Group age above av. Life exp. Of the total population. (SF-12v2/LHS questionnaire)	• Group age below av. Life exp. Of the total population. (SF-12v2/LHS questionnaire)
	• Purpose- assess, diagnosis, treatment (staff) and monitoring, check-up (SU) solve problems (Carer) (Int.18,19/OPD/service user) • No negative care experiences.	• Purpose- 'Promote and Maintain independence'(Int.4,3/RT/staf); giving training on how to live independently (SU) (Int.2/RT/Service user); looking at service user circumstances, building a rapport with the carer (Carer) (Int. 6/RT/carer). • Nurturing independence and dignity (Int.1,4/RT/staff/service user) • No negative care experiences.	• Purpose- promoting independence (staff) (Int.23/dayhospital/staff); assessment diagnosis and information (SU) (Int.21,22/dayhospital/service user/carer; Obs.1/dayhospital, Wallace, 2002; solve problems and help to live with disease (Int.22,24/dayhospital/service user/carer.) • Being in control (Int.21,22/dayhospital/service user/carer) • Negative care experience: Some not wanting to attend (Obs.1/dayhospital) .Disempowering language expressed (Obs.1/dayhospital)	• Purpose- for socialization and personal hygiene (Int.10/daycare/staff); avoid depression and social isolation (SU) (Int.8,9/daycare/service user); respite (Carer) (Int.7/daycare/carer) • Relief of being lonely (Int.11,8/daycare/service user,; Int14/JDC/service user) • Negative care experience: Some potential service users refusing to attend (Int.6/RT/carer). Disempowering language expressed (Obs.5/Daycare; Int.6/RT/carer).	• Purpose-To promote independence and improve quality of life' and 'prevent admission' (Int.12,17/JDC/staff); to feel valued as a person, a communication centre, escape isolation (SU) (Obs.4/JDC/Daycare; Int.1314, 15, 16/JDC/carer/service user,); reliable and regular respite and care (Int.13,16/JDC/carer/service user,) • Relief of being lonely (Int. 8,11/daycare/service user;Int14/JDC/service user) • Negative care experience: Some potential service users refusing to attend (Int.4/RT/Staff). Different opportunities available for young and older attendees (Int.1/RT/Service user)
	• Grey space- experiencing pain (Int.18/OPD/service user)	• Grey space- afraid of walking outside (Int.1,,2,4/RT/Service user,staff); social isolation self imposed (Int.4/RT/Staff)	• Grey space- none	• Grey space- social isolation imposed by others (Int.9/daycare/service user; Obs.8/RT/daycare). Experiencing pain (Int.8/daycare/service user)	• Grey space- experiencing pain (Int.12/JDC/staff)
	• Leutz (2005) level of integration = Linkages	• Leutz (2005) level of integration = Integrated team with generic workers	• Leutz (2005) level of integration =co-ordinating services (Wallace, 2002; PF 3/dayhospital).	• Leutz (2005) level of integration = Linkages (PF4/day care;	• Leutz (2005) level of integration = coordinating services (Int3/RT staff;

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
	(Obs.3/OPD, Int.25/OPD/staff, PF1/OPD)	(Int.3,4,5/RT/Staff,; PF 2/RT).		Int.10/daycare/staff).	PF5/JDC)
	• Adapted Boon et al (2004) = consultative team (PF1/OPD, Obs.3/OPD, Int.19,25/OPD/service user,staff)	• Adapted Boon et al (2004) = integrative (Int. 1-6/RT/sevice user/staff/carer; CRP, 2003;CRP, no date; BGHA, 2002, BGLHG et al, 1999,BGLHG, 2002; GHCT, 2001;BGSSD,2001-2002; GHCT, 1999-2001; GHCT, 2001; PF2/RT. Obs.9/RT/dayhospital)	• Adapted Boon et al (2004) = coordinated team (Obs.1,9/dayhospital,;Wallace, 2002; Int.22,23/dayhospital/service user/carer.; PF.3/day hospital)	• Adapted Boon et al (2004) = parallel practice (Int.7/daycare/carer-11; Obs.4,6/JDC/Daycare, , PF.4/daycare; BGCBC,2001/2002/2003)	• Adapted Boon et al (2004) = multi-agency/multidisciplinary approach (Int.3/RT/Staff; Int.12-17/JDC/staff/service user/carer;PF5/JDC;Upton, 2003, Obs.7/JDC)
	• Service user/carer relationship: Active service user coordination-independent living (Int.19,20/OPD/service user;)	• Service user/carer relationship: Active Service User Coordination-supported living (Int. 1,2/RT/service user). Collaborative relationship (during crisis)(Int.1,2/RT/Service user,)	• Service user/carer relationship: Collaborative relationship (Int.22/dayhospital/service user/carer)	• Service user/carer relationship: Carer coordination control (Int.7/daycare/carer)	• Service user/carer relationship: Carer coordination control (Int.15,16/JDC/service user,)
Why integrated services were perceived as different to non integrated services?	• OPD not included in day service reviews	Developed from the review of day hospital (study group 3), day centre (study group 4) • 1999 Business case and model • 2001 New flexibilities and pooled budget (BGLHB & BGCBC,no date; Wallace & Lane, 2002; GHCT, 1999-2001) • 2001 QNI award (District Audit, 2001;GHCT, 1999-2001) • 2002 Day hospital review (GHCT, 2003-2004; SSD, 2002-2003;Wallace, 2002; RT, 2000-2004)	The equivalent service reviewed to develop study group 2 and 5. • 1996 review (Wallace & Lane, 2002; BGLHG et al, 1999, BGCBCSSD, 1997-2000; O'Leary, 1999, GHCT, 1999-2001) • 1999 Service user satisfaction survey (Wallace & Lane, 2002; BGLHG et al, 1999; Unknown, no date; BGLHG et al, 1999; O'Leary, 1999) • 2002 Day hospital review (GHCT, 2003-2004; SSD, 2002-2003;Wallace,2002; RT, 2000-2004) • Service Evaluation (UWIC) (GHCT, 2003-2004;RT, 2000-2004;BGSSD,2001-2002; CRP, 1999-2004)	One of the original services reviewed to develop study group 2 and 5. • 1999 Service user satisfaction survey (Wallace & Lane, 2002; BGLHG et al, 1999; Unknown, no date; BGLHG et al, 1999; O'Leary, 1999)	Developed from the review of day hospital (study group 3), day centre (study group 4). • 1996 review (Wallace & Lane, 2002; BGLHG et al, 1999, BGCBCSSD,1997-2000, O'Leary, 1999, GHCT, 1999-2001) • Service user satisfaction survey (Wallace & Lane, 2002; BGLHG et al, 1999; Unknown, no date; BGLHG et al, 1999; O'Leary, 1999) • Service Evaluation (UWIC) (GHCT, 2003-2004;RT, 2000-2004;BGSSD, 2001-2002; CRP, 1999-2004)

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
		• Service Evaluation (UWIC) (GHCT, 2003-2004;RT, 2000-2004;BGSSD, 2001-2002;CRP, 1999-2004) 2003 JDC & RT based together in community hospital, then move to leisure centre. Co-location ended (GHCT, 2003-2004;BGLHG, 2002-2003; BGLHB & BGCBC, no date; RT, 2000-2004, BGSSD, 2001-2002; BGSS, 2003-2004; Int.12/JDC/staff) • Project management structure (Upton, 2003; CRP, 2001; CRP, 2001-2003b; BGCBC, 2001-2003; GHCT, 2001; BGLHG et al, 1999; CRP, 1999-2004; CRP, 2001; BGLHB, 1999-2003; BGSS, 2003-2004)			• 2003 JDC & RT based together in community hospital then move to leisure centre. Co-location ended. (GHCT, 2003-2004; BGLHG, 2002-2003; BGLHB & BGCBC, no date; BGSS, 2003-2004, RT, 2000-2004, BGSSD, 2001-2002; Int.12/JDC/staff)
	• Strategically linked through role of LHB HSCWB partnership board (GHA/BGCBC, 2002-2007; BGLHG (2002-2003))	• Strategically linked through role of LHB HSCWB partnership board (GHA/BGCBC, 2002-2007; BGLHG, 2002-2003)	• Strategically linked through role of LHB HSCWB partnership board (GHA/BGCBC, 2002-2007; BGLHG,2002-2003)	• Strategically linked through role of LHB HSCWB partnership board (GHA/BGCBC, 2002-2007,; BGLHG, 2002-2003)	• Strategically linked through role of LHB HSCWB partnership board (GHA/BGCBC, 2002-2007; BGLHG, 2002-2003)
	• No operational policy	• Operational policy and statement of purpose originally developed in 2001 linked to needs assessment and HSCWB strategy (BGLHB & BGCBC et al, 2005-2008)	• No operational policy	• No operational policy (BGCBC,2001/2002/2003)	• Statement of purpose (Wallace & Lane, 2002)
	• Staff employed by NHS	• Staff employed by both NHS and LA (Upton, 2003;	• Staff employed by the NHS (Wallace,	• Staff employed by CBC	• Staff employed by CBC

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
	(Int.25/OPD/ Staff)	CRP, 2001;CRP, 2001-2003b; BGCBC,2001-2003;GHCT, 2001; BGLHG et al, 1999; CRP, 1999-2004; CRP, 2001-BGLHB, 1999-2003; BGSS, 2003-2004)	2002)	(Int.10/daycare/staff)	(Int.12/JDC/staff, 17)
	• service data unavailable	400 referrals April 2005-Jan 2006 (Quantitative service data)	• 198 referrals April 2005-Jan 2006 (Quantitative service data)	• 13 referrals April 2005-Jan 2006 (Quantitative service data)	• 22 referrals April 2005-Jan 2006 (Quantitative service data)
	• Referral route via GP (PF 1)	• Referral route 63% hospital (DGH); 37% Community setting; 0% SSD via social worker (quantitative service data)	• Referral route 22% Hospital (DGH); 78% Community setting; 0% SSD; 0% RT (quantitative service data)	• Referral route 100% SSD via social worker (quantitative service data)	• Referral route 91% SSD via social worker; 9% RT. (quantitative service data)
	• SF12v2 on referral: Participants from Study Group 2 (RT) perceived a worse health status in social functioning than Study Group 1 (OPD). • SF12v2 1st and 2nd stage –respondents of non-integrated services had significantly more pain interfering in their normal day in phase 2 than they experienced during 1 i.e. in referral to the service.	• SF12v2 on referral: Participants from Study Group 2 (RT) perceived a worse health status in social functioning than Study Group 1 (OPD). • Participants from Study Groups 2 (RT) perceived a worse health status in role emotional than Study Group 4(CM). • LHS upon referral: Study Group 2(RT) are more disadvantaged in their mobility than Study Group 1(OPD) • SF12v2 1st and 2nd stage: Therefore respondents had significantly more pain interfering in their normal day in phase 2 than they experienced during phase 1 i.e. on referral to the service.	• SF12v2 on referral: None • LHS upon referral: Study Group 3 (YMDH) are more disadvantaged in economic self sufficiency than Study Group 4(CM). • SF12v2 1st and 2nd stage –respondents of non-integrated services had significantly more pain interfering in their normal day in phase 2 than they experienced during 1 i.e. in referral to the service.	• SF12v2 on referral: Participants from Study Groups 2 (RT) perceived a worse health status in role emotional than Study Group 4(CM). • SF12v2 1st and 2nd stage – respondents of non-integrated services had significantly more pain interfering in their normal day in phase 2 than they experienced during 1 i.e. in referral to the service.	• SF12v2 on referral: Participants from Study Group 5 (JDC) experienced worse health status in role emotional than Study group 4(CM). • Study Group 5 (JDC) are more disadvantaged in their mobility than Study Group 1 (OPD). • Study Group 5(JDC) are more disadvantaged in occupation than Study Group 1 (OPD).

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
	Setting: Outpatient dept. in hospital (Obs.3/OPD).	• Service User's own home (Int.1-6/RT/Carer/service user/staff; Obs.9/RT/day hospital)	• Provided in purpose built day hospital accommodation within community hospital (Obs.9/RT/Dayhospital; Wallace, 2002)	• Provided within two rooms within a day care unit in statutory care home (Obs.6/Daycare; BGCBC, 2001/2002/2003).	• Provided within purpose built day care accommodation in Leisure centre(GHCT, 2003-2004; BGLHG, 2002-2003; BGLHB & BGCBC,no date;BGSS,2003-2004,RT, 2000-2004;BGSSD,2001-2002; Int.12-17/JDC/staff/service user/carer)
	Type of care: Non-urgent/routine Planned (Int.25/OPD/Staff, Obs.3/OPD, PF1/ OPD)	Type of care: Urgent/non-urgent/routine/ Planned (PF 2/RT, .Wallace & Lane, 2002; Int. 1-6/RT/staff/service user/carer)	Type of care: Non-urgent/routine/ Planned (PF.3/day hospital; Wallace,(2002;)	Type of care: Non-urgent/routine/ Planned (PF4/day care, Int. 7-11/day care/service user/carer/staff)	Type of care: Non urgent/ routine/ planned (PF5/JDC;Wallace & Lane, 2002; Int.12, 17/JDC/staff,)
	Networks: Extensive clinical networks in health organisations (Int.25/OPD/Staff, Obs.3/OPD)	Networks: Extensive clinical, professional and managerial networks across statutory and non-statutory organisations (CRP, 2003;CRP, no date; BGHA (2002), BGLHG et al, 1999,BGLHG, 2002;GHCT, 2001;BGSSD,2001-2002)	Networks: Clinical and Health organisation and limited others. Which include social work and care and repair. (PF.3/day care; Int. 22, 23/dayhospital/staff/service user/carer)	Networks: Limited, formal network to Social work and informal district nursing only (Int.10/daycare/staff)	Networks: Formal to social work and RT, Informal to Leisure (swimming, gym), fire, education, (computer skills, arts/ crafts) police, Age Concern, schools (primary and secondary) (Wallace & Lane, 2002; Int. 14,17,16/JDC/staff/service user/carer)
	Management arrangements: Medical director NHS Trust (Int.25/OPD/Staff)	Management arrangements: Originally Joint Health and Social Care appointment until 2004. Now Team manager, Borough Manager NHS Trust (GHCT, 1999-2001).	Management arrangements: Borough Manager, Day hospital manager manages nurses only within unit, NHS Trust. Allied health professionals managed by their own departments (Wallace, 2002)	Management arrangements: Hierarchy of care assistants, 3rd officer, 2nd officer and Officer in charge, Head of provider Services, Social Services L. A. (BGCBC, 2001/2002/2003)	Management arrangements: Hierarchy of Care assistant, Day Services Officer, Day Services Manager, Head of Provider Services, Social Services, L.A. (Wallace & Lane, 2002; Int.12/JDC/staff)
	Assessment and service provision	Assessment and service provision co-located within the	Assessment and service provision co-located within the core team only (PF.3/day	Assessment and service provision Separate	Assessment and service provision Separate

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5
	Separate (Obs.3/OPD)	core team only (PF. 2/RT; Int. 3,4,5/RT/staff)	hospital; Obs.9/RT/dayhospital)	(PF.4/day care; Int.10, 11/daycare/staff/service user,)	Formal, Informal assessment in-house (Int. 12,17/JDC/staff,)
	Referral from GP. Formal referral used to others (PF1/ daycare)	Referral not required within the RT only to social services and other services outside of the RT (PF2/ Dayhospital)	Formal referral between team members and to others with use of appointment cards for service users to see allied health professionals (Wallace,2002; Obs.1/dayhospital)	Formal process of referral from Social work only (PF.4/daycare, Int.10,11/daycare/staff,/service user)	Formal process of referral from social work and RT. Informal with leisure (PF.5/JDC, Int.17/JDC/staff)
	Treatment planning (PF1/ OPD; Obs.3/OPD)	Service user goal planning (PF2/ RT; Int. 5/RT/staff)	Treatment Planning (PF.3/day hospital.)	Care plan received from social worker (Int.10/daycare/staff)	Care plan from social work referred service users; Service user aims and objectives. RT service user goal planning. (Int. 3/RT/staff; Int, 17, 12/JDC/staff)
	Assessment: Consultant assessment (PF1/ OPD; Int.25/OPD/staff, Obs.3/OPD)	Assessment: Generic assessment for core team-specialist assessments when needed (PF 2/RT; Int. 3,4,5/RT/staff)	Assessment: Separate MDT assessments (PF3/JDC; Int.23/dayhospital/staff)	Assessment: No assessment in study group- social work assessment prior to referral (Int.10/daycare/staff)	Assessment: Formal (outside of unit) and informal assessment (Int.12,17/JDC/staff,)
	Lead assessor: Consultant autonomy (PF1/ OPD; Int.25/OPD/staff, Obs.3/OPD)	Lead assessor: None- duty manager designates according to service user need (PF 2/RT; Int. 4/RT/staff)	Lead assessor: Consultants (including Parkinson's, PEG, Rheumatology, Medical, Dermatology) (Wallace, 2002; Obs.1/dayhospital,;Int.22/dayhospital/service user/carer)	Lead assessor: None in centre -social worker autonomy (Int.10/daycare/staff)	Lead assessor: RT inside the unit and social work outside of the unit dependant upon service user need (Upton, 2003)
	Medical records (Obs.3/OPD, Int.25/OPD/staff)	Joint documentation developed by the whole team. Medical notes used for information only (CRP, 2001-2003a; RT, 2005-2008)	Medical records (Obs.9/RT/dayhospital)	No-Day care notes for day care use only (Obs.4/JDC/Daycare)	Care plan and care notes, RT plan, exercise plan (Int.12,17/JDC/staff,)
	No appointed care co-ordinator. (PF 1/OPD).	Single care co-ordination role within the core team to build team consensus (Int.5/RT/Staff)	Information gathering by sister (Obs.1/dayhospital; Wallace,2002)	No appointed care co-ordinator (Int.10/daycare/staff)	Care assistant as Key worker, JDC manager as information gatherer. (Int.17,16,12/JDC/staff/service user/carer)

Study questions	Study Group 1	Study Group 2	Study Group 3	Study Group 4	Study Group 5

Glossary of Terms

Term used	Definition
Bottleneck	'any part of the system where patient flow is obstructed' (WAG, 2002c)
BGCBC	Blaenau Gwent County Borough Council
BGLHB	Blaenau Gwent Local Health Board
BGLHG	Blaenau Gwent Local health Group
Capacity	'The resources available to undertake work at a specific step in the patient's pathway'(WAG, 2002c)
Carer or care giver	A relative or friend who provides continuing care, usually without pay and motivated by a personal relationship with the care recipient; also known as 'informal carer'(Mason et al, 2007)
Community Reablement	Primarily concerned with admission avoidance, supporting discharge from hospital and rehabilitation in the home setting. Community Reablement schemes vary in their skill makeup, their specialism in these areas and their level of joint working (Peet et al, 2002)
CP	Community Physiotherapist
Day Hospital	First opened in 1953 (Brocklehurst and Tucker, 1980; Brocklehurst, 1970, 1995). Morishita (1988, p202) described the Geriatric Day Hospital (GDH) as 'a unique model of hospital outpatient care for frail elderly people….. [which]…. provides interdisciplinary team care and acute hospital services during the day between the hours of 8.30am and 5pm.'
Day Centre	Day care is a traditional concept which is usually described as a service provided within a centre (Clark, 2001). This is a service provision for frail, vulnerable or elderly groups of people (Wright, 1995). Although in the past some have been attached to multi-purpose care homes with the purpose of creating a link between day care and home so that the fear of moving into a care home if necessary was reduced (Wright, 1995).
Rapid Response	A service which provides 24-hour assessment, acute nursing care and social support in collaboration with medical cover (e.g. GP), allied health and social professional support in an older patient's own homes. Its purpose is to reduce the rate of emergency admissions (Oh et al, 2009).
Service Demand	'The requests and referrals coming from all sources to the pathway step' (WAG, 2002c)

Direct payments	A financial arrangement in the UK whereby individuals receive a cash payment to manage and organise their own care arrangements in lieu of services (Mason et al, 2007)
Enablement	'The process of helping the individual to achieve what is important to her/him, to respond to her/his circumstances, to assert her/his individuality and establish her/his goals' (Stewart 1994 cited in Creek, 2003).
DoH	Department of Health
Elective	'Planned work (non-emergency), for outpatient, daycase and inpatient activity usually emanating from referrals or waiting lists' (WAG,2002c)
GP	General practitioner
GHA	Gwent Health Authority
GHCT	Gwent Healthcare NHS Trust
HSCWB	Health Social Care and Well Being Strategy
IC	Intermediate Care
LHB	Local Health Board
MDT	Multi-disciplinary team
NAfW	National Assembly for Wales
NHS	National Health Service
ONS	Office for National Statistics
OT	Occupational Therapist
OPM	Office for Public Management
Outpatient	'a person attending by arrangement (usually at an outpatient department) to see a consultant (or GP acting as a consultant), a member of his firm or a locum for such a member' (WAG, 1999-2007)
SSD	Social Services Department
Syndrome	'a combination of signs and/or symptoms that forms a distinct clinical picture indicative of a particular disorder' ("syndrome n" Concise Medical Dictionary, OUP, .2007)
UN	United Nations
'Value demand'	Demand created by what the service user wants the service to provide (Seddon, 2008)
WAG	Welsh Assembly Government
WHO	World Health Organisation