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The development of a chronic conditions management service: A case study of health and social care integration.

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The Development of a Chronic Conditions Management Service: A Case Study of Health and
Social Care Integration

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Abstract

This thesis explores integrated working in chronic conditions management (CCM). With recent demographic change witnessing a significant worldwide growth in the numbers of people living with chronic conditions (World Health Organization, 2014), these are people whose care needs, many argue, are best served by way of integrated care (Goodwin et al., 2012). The latter's organising principle, it is widely agreed, should be the service user perspective and its fundamental objective the improvement of their care (Goodwin et al., 2012). Existing research, however, has largely failed to take account of the views of service users and of the outcomes they value (Cameron et al., 2012). This thesis seeks to address these issues. It is a qualitative case study of the introduction of an integrated health and social care community CCM service in a Welsh locality during a Welsh Government initiative, focusing on the development of integrated care for people living with chronic conditions and the involvement of service users. It combined: non-participant observation of meetings; individual semi-structured interviews with lead-agency representatives, people living with chronic conditions, carers, referrers to the new service and voluntary/third sector representatives; focus groups with front-line health and social care professionals; and documentary research. The study incorporates an original combination of topics and examination of service user and carer perspectives, an examination of previously unexplored contextual factors and an original application of analytical and conceptual approaches. In so doing, it highlights the way in which inadequate funding, concurrent structural reform, conflicting strategies, unclear objectives and time-pressures militated against the involvement of service users and changes to their experience of care and that the initiative, consequently, did not deliver an integrated service. These factors point to a need for a more carefully considered governmental approach to CCM and integration and a requirement for more service user-focused research.

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ...   . (candidate)

Date ....1./.6./.1.5.

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Contents

Acknowledgements

List of Tables

List of Figures

Abbreviations

AC	Audit Commission
BMA	British Medical Association
CCM	Chronic Conditions Management
CDM	Chronic Disease Management
CHC	Community Health Council
COPD	Chronic Obstructive Pulmonary Disease
CRT	Community Resource Team
CSIP	Care Services Improvement Partnership
CVD	Cardiovascular disease
DH	Department of Health
EPP	Expert Patient Programme
GP	General Practitioner
HSCWB	Health Social Care and Wellbeing
HWBPIB	Health and Wellbeing Best Practice and Innovation Board
ICN	Integrated Care Network
IDeA	Improvement and Development Agency
IRAS	Integrated Research Application System
LHB	Local Health Board
LLT	Locality Leadership Team
LREC	Local Research Ethics Committee
LSB	Local Service Board
LTC	Long-term condition
MS	Multiple sclerosis
NAW	National Assembly for Wales
NCD	Non-Communicable Disease
NCICS	National Collaboration for Integrated Care and Support
NHS	National Health Service
NIA/NIH/USDHHS/WHO	National Institute on Aging/National Institutes of Health/US Department of Health and Human Services/World Health Organization
NICE	National Institute for Health and Care Excellence
NLIAH	National Leadership and Innovation Agency for Health care
NMC	Nursing and Midwifery Council
NPCRDC	National Primary Care Research and Development Centre
NPHSW	National Public Health Service for Wales
NSF	National Service Framework
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
PACE	Program of All-inclusive Intensive Care for the Elderly
PCT	Primary Care Trust
PID	Project Initiation Document
PPI	Patient and Public Involvement
PRB	Population Reference Bureau

PRISMA	Program on/of Research for Integrating Services for the Maintenance of Autonomy
RCN	Royal College of Nursing
RCT	Randomised controlled trial
REC	Research Ethics Committee
RCP/RGP/NHS Alliance	Royal College of Physicians/Royal College of General Practitioners/NHS Alliance
SCIE	Social Care Institute for Excellence
SIPA	Système de Services Intégrées pour les Personnes Âgées en Perte d'Autonomie
UK	United Kingdom
UN	United Nations
U.S.	United States
USGAO/PEMD	The United States General Accounting Office Program Evaluation and Methodology Division
WAG	Welsh Assembly Government
WAO	Wales Audit Office
WG	Welsh Government
WHO	World Health Organization
WMA	World Medical Association
YLL	Years of Life Lost

Data Identifiers

BLMO:	Building the Locality Meeting Observation
CLI:	Client interview
EMA:	Email correspondence
FNMO:	Field-notes Meeting Observation
FPCO:	Front-line professional consultation observation
FPFG:	Front-line professional focus group
GPI:	General Practitioner Interview
ICI:	Informal carer interview
JLLTMO:	Joint Locality Leadership Team Meeting Observation
LARI:	Lead Agency Representative Interview
LLTMM:	Locality Leadership Team Meeting Minutes
LLTMO:	Locality Leadership Team Meeting Observation
MMO:	Managers' Meeting Observation
MP:	Management Presentation
RD:	Reflexive Diary
RMO:	Review Meeting Observation
VSRI:	Voluntary sector representative interview

Chapter 1: Introduction

Background

This thesis explores the integration of care services for people living with chronic conditions. With recent demographic change seeing a major global growth in the numbers of people living with chronic conditions (World Health Organization [WHO], 2014), these are people whose care needs, many argue, are best met by integrated care (Goodwin et al., 2012). The latter's organising principle, it is widely agreed, should be the service user perspective and its fundamental objective the improvement of their care (Goodwin et al., 2012). Existing research, however, has largely failed to take account of the views of service users and of the outcomes they value (Cameron et al., 2012). I attempt to address this research-gap in this thesis, a qualitative case study of the introduction of a new integrated health and social care community Chronic Conditions Management (CCM) service in the Bro-y-Grug locality of the south Wales unitary authority of Armorshire. (For purposes of anonymity and confidentiality, Bro-y-Grug and Armorshire are pseudonyms, as are the names of all of the places and people directly involved in the introduction of this service, unless otherwise indicated). I do this by considering, from an interpretevist standpoint and drawing on multiple data-collection methods, the way in which integrated care for people living with chronic conditions developed during the implementation of the new service. The latter was inaugurated during Bro-y-Grug's participation – as part of the Armorshire demonstrator-site – in Wales' National CCM Demonstrator Programme.

In this opening chapter, I discuss the terminology and characteristics of chronic conditions, before exploring the rise in prevalence of chronic conditions worldwide amidst demographic change. I examine the impact these changes are having on global health and social care systems, describing how existing systems were not designed to manage the complex, multiple and long-term needs of people living with chronic conditions, but according to an acute and episodic model of care. I discuss the importance of self-management, empowerment and involvement to chronic conditions care. I describe how different countries have sought to address current pressures on health and social care systems by looking to disease management and,

1

in particular, to integration. I review the Welsh CCM Model and Framework, explaining that this, likewise, is premised on integration, self-management, service user involvement and empowerment. Subsequently, I outline the National CCM Demonstrator Programme and provide some background information about the Bro-y-Grug locality. I describe my own interest in integrated working and the care of people living with chronic conditions, prior to setting out the study's aim and objectives. I end the chapter with an overview of the remainder of the thesis.

Chronic conditions: terminology and characteristics

Alabaster (2006) suggests that an analysis of terminology is an essential starting point for any discussion related to the field of chronic conditions, but adds that its multifaceted nature militates against definitional precision. Indeed, this is reflected in the fact that in the Department of Health (DH) publication *Improving Chronic Disease Management* (DH, 2004, p. 1) it is noted that a number of terms – such as 'chronic condition', 'chronic disease', 'life-long disease/condition', 'long-term disease/condition' and 'non-communicable disease/condition' – are used interchangeably. Extending this list to include, 'chronic illness' and 'chronic illness and disability', Wellard (2010) likewise refers to the interchangeable use of terms, before adding that related literature is characterised by a frequent failure to acknowledge differences or define terms clearly. This, despite stressing that such a lack of clarity can, 'blur meanings and assumptions inherent in the arguments presented by authors' (2010, p. 2). (It is of note that a lack of clarity and consensus *vis-à-vis* terminology, definitions, meaning and conceptualisation[1] is a feature of many of the themes discussed in this thesis, as will become apparent in the course of this and subsequent chapters).

Whilst it is beyond the scope of this thesis to examine the differences between the many terms used within the field, it is perhaps helpful to clarify some basic concepts. Chronicity, first of all, relates to the temporality of a condition where changes in health are ongoing and cannot be cured by a short course of treatment or surgery (Miller, 2000). Disease, secondly, refers to the assignment of a diagnosis (Wikman et al., 2005) or the practitioner's view of pathophysiological alterations in a person's

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[1] Conceptualisation, according to Brett et al. (2009, p. 31) is, 'the way a phenomenon is described, defined and understood'

condition associated with an objective medical view of a human ailment (Hofmann, 2002). Illness, thirdly, refers to the perceived human experience of living with and responding to disease (Taylor, 2005) and its subjective interpretation (Hofmann, 2002). Disability, finally, identifies any long-term or permanent loss or reduction in functional capacity (Alabaster, 2006).

As for the use of 'condition', Wellard (2010) notes that this has emerged as part of a recent movement to create, 'an umbrella term that will be inclusive of the different understandings of chronic ailments and link different audiences to look more at the overarching issues related to chronicity in the world'. In England, frequent reference is made to *long-term* conditions (LTCs) (see, for example, DH, 2008; 2010; 2012) whereas in Wales, frequent reference is made to *chronic* conditions (see, for example, Welsh Assembly Government [WAG][2], 2007; 2008; Wales Audit Office [WAO]; 2008; 2014). The definitions adopted in both countries, however, draw attention to the life-changing impact of living with a condition from which there is currently no hope of recovery:

> LTCs are those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies. The life of a person with a LTC is forever altered – there is no return to 'normal' (DH, 2008, p.10).

> Chronic conditions are those which in most cases cannot be cured, only controlled, and are often life-long and limiting in terms of quality of life. They can require differing levels of support due to disease progression or the fluctuating nature of the disease (WAG, 2007, p. 7).

Given the range of terminology used in this field, I make use of a variety of terms in this thesis, but for the most part employ the term chronic condition. Firstly, because the locality in which the new CCM community service that I researched was in Wales; secondly, because condition is a term which, Wellard (2010) points out, is used increasingly in health and social care projects – like the introduction of the new CCM service in Bro-y-Grug – that involve a number of different stakeholders[3]. According to O'Halloran et al. (2003, p. 100), 'Chronic conditions may be characterised by the following criteria: a duration that has lasted, or is expected to

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[2] In keeping with current usage, I use the term 'Welsh Government' throughout this case study.
[3] Stakeholders, according to Crosby and Bryson (2005, p. 22) are the, 'individuals, groups, or organisations that are affected by a public problem, have partial responsibility to act on it, or control important resources'.

last, 6 months; an insidious onset; an uncertain or poor prognosis; and the possibility of sequelae'. Alabaster (2006), likewise, notes that chronic conditions are generally associated with the presence of a protracted disease process – often considered as one which lasts for more than six months – which results in impairment or disability, and which is not amenable to treatment.

Carrier (2009), in turn, specifies that all chronic conditions continue indefinitely but that there is no single onset pattern, and adds that there can be long periods of remission with an absence of symptoms punctuated by episodic exacerbations. Carrier (2009) notes that the list of chronic conditions is long, including: diabetes, cardiovascular disease, chronic kidney disease, chronic obstructive pulmonary disease and musculoskeletal diseases such as arthritis and osteoporosis; neurological conditions such as epilepsy, multiple sclerosis, Parkinson's disease and motor neurone disease; skin conditions such as psoriasis and eczema; genetic conditions such as cystic fibrosis and muscular dystrophy; and mental conditions such as schizophrenia and dementia. Significant improvements in the diagnosis and treatment of cancer mean that this too can be understood as both an acute and chronic illness (Tritter, 2009). Similar advances have also rendered a number of communicable diseases chronic, such as HIV and AIDS (Richardson, 2009). Depression, too, is a long term condition and is considered by some to be more common than many of its physical counterparts (Mitchell et al., 2009).

Alongside the diversity of terms used to designate ailments characterised by their chronicity, it has been indicated that a diversity of terms are used to denote people who currently use health and social care services (which includes people living with chronic conditions) and members of the wider public who may need to do so at some future time (Hanley et al., 2004). Accordingly, reference is made, *inter alia*, to, 'the community', 'the public', 'clients', 'patients', '(service) users', 'survivors[4]' 'citizens[5]', 'taxpayers', 'consumers' and 'lay people[6]'. However, it is argued that –

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[4] In the field of mental health services, 'survivor' is sometimes the preferred term in the UK, reflecting some service recipients' objections to the term 'service user' (Rogers and Pilgrim, 2010).
[5] Beresford and Croft (1993) indicate that notions of 'citizens' and of 'citizenship' are contested and explain that whereas the 'political right' often conceptualise citizenship in terms of obligations and responsibilities, the 'political left and centre' often do so in terms of a basis for people's rights.
[6] According to Hogg and Williamson (2001, p. 3), 'lay people' are, 'those who have not gone through the training or the socialisation into the particular profession under discussion'.

4

despite having divergent meanings and connotations – these designations are often unclearly defined and arbitrarily interchanged (see, for instance, Boote et al., 2002; Wait and Nolte, 2006; Conklin et al., 2010; 2012; Naidoo and Wills, 2011; Baggott, 2011; Mockford et al., 2012).

Focussing on people living with chronic conditions, it is widely recognised that their care needs are complex and span many different health and social care services (a subject to which I return later in this chapter). It is therefore of note that whilst Martin et al. (2010, p. 93) point out that 'patient' and 'client' are the favoured terms used in health care and social care respectively, they add that 'service user' is neutral; as for the lay-person who provides a significant amount of support to a person who is in need of both health and social care, Martin et al. (2010, p. 93) explain that she or he is often termed 'carer'. Given that in this thesis I explore the creation of a service that sought to integrate health and social care – and in keeping with their common usage in current Welsh Government (WG) documentation (see, for instance, WAG, 2007; 2008; WG, 2012; 2013) – for the most part I therefore employ the terms service user and carer.

Having discussed issues of language and characteristics pertaining to the field of chronic conditions, set out some of the different conditions that can be considered chronic and explored some of the terms used to describe the users (and potential users) of services, in the next section I discuss the growing prevalence of chronic conditions worldwide.

Demographic change: increasing numbers of people living with chronic conditions

In a joint-report on global ageing by the National Institute on Aging (NIA)/National Institutes of Health (NIH)/United States Department of Health and Human Services (USDHHS) and the WHO (2011, p. 2) it is noted that the world is on the brink of reaching a, 'demographic milestone'. The milestone, it is explained, is that for the first time in recorded history, the numbers of people aged sixty five or older in the world will soon outnumber children aged under five. It is further noted in the report that the 2010 global population of an estimated 524 million people aged sixty-five or older is projected to grow to nearly one and a half billion by the year 2050.

5

Focussing on Europe, in a WHO (2012) publication strategy and action plan on ageing, it is reported that the European Region has the world's highest median age and that residents of many European countries have some of the world's highest life expectancies. It is further noted that the population of Europe is ageing rapidly and that, according to current estimates, by the year 2050 around a quarter of people will be aged sixty-five or older. In an Office for National Statistics (ONS) report on population ageing across Europe and in the UK (ONS, 2012), it is indicated that the latter's population is ageing and that this trend is expected to continue over the coming decades. Of the UK's four constituent countries, moreover, attention is drawn in the same report to the fact that Wales was consistently the most aged between 1985 and 2010 and that it currently has the highest median age and highest proportion of people aged sixty-five or over. Indeed, with eighteen percent of the population of Wales already aged sixty-five and over (National Public Health Service for Wales [NPHSW], 2006), this figure is projected to increase to around thirty-two percent between 2010 and 2026 (WG, 2013).

Moreover, the ONS (2013) reports that women and men now aged sixty-five in England and Wales are expected, on average, to live for another twenty-one and nineteen years respectively. Indeed, according to the NIA/NIH/USDHHS/WHO (2011), the number of people aged eighty-five and older (whom, Glasby [2012, p. 47] notes, are often termed the 'oldest old') is burgeoning worldwide, and in many developed countries is the fastest growing part of the population. With the number of people aged eighty-five and over in England and Wales having doubled in the past three decades (ONS, 2013a), the highest proportion (five percent) of people aged eighty and over of any part of the UK lives in Wales (WG, 2013d). Furthermore, it is currently predicted that by the year 2020, the proportion of people aged eighty-five and over in Wales will increase by twenty-two percent (Daffodil, 2014).

Many of the reasons for these demographic changes can be traced back to advances in medical care, better public and preventive health measures and improvements in the socio-economic well-being of populations (ONS, 2009; Sadana et al., 2013). The NIA/NIH/USDHHS/WHO (2011) reports that greater longevity can, in part, be attributed to public health projects carried out in the course of the twentieth century that immunised millions of people against contagious diseases (such as smallpox,

6

polio and measles) as well as to improved living standards, more nutritious diets and cleaner drinking water, all of which have helped reduce serious infections and prevent deaths. But the significant fall in morbidity and mortality due to infectious and acute diseases, adds the NIA/NIH/USDHHS/WHO (2011, p. 9), has been accompanied by a marked rise in chronic and degenerative diseases, in a major shift which demographers and epidemiologists have labelled the, 'epidemiological transition' (see, for instance, WHO, 2002; 2014a).

With a significant growth in the incidence of chronic conditions witnessed in industrialised and affluent nations (Wellard, 2010) similar issues are also affecting parts of the developing world (WHO, 2011). Globally, the proportion of years of life lost (YLL)[7] resulting from non-communicable diseases (NCDs) increased from thirty-eight percent in 2000 to forty-seven percent in 2012 (WHO, 2014a). Chronic conditions currently account for sixty-three percent of all global fatalities (WHO, 2011) seventy-two percent of the global disease burden of people aged over thirty (Strong et al., 2005) and eighty-six percent of all fatalities and seventy-seven percent of the disease burden in Europe (WHO, 2007b). NCDs are currently the leading cause of death in all of the world's countries bar sub-Saharan Africa (Population Reference Bureau [PRB], 2012). In some parts of Europe, as many as forty percent of people aged fifteen or over report a long-standing health problem (European Commission, 2007). In the United Kingdom (UK), more than seventeen and a half million adults report living with a chronic health problem (DH, 2005). In Wales, one third of all adults (800,000 people) report having at least one chronic condition (National Public Health Service for Wales [NPHSW]/Welsh Assembly Government [WAG], 2006).

Furthermore, a growing number of people are living with more than one chronic condition, explain Jadad et al. (2010). Reporting that there is 'no accepted terminology for this phenomenon', Jadad et al. (2010, p. 21) note that the terms most commonly used are, 'comorbidity', 'polypathology', 'pluripathology', 'multimorbidity', 'multipathology' and 'complex chronic disease'. Irrespective of

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[7] According to the WHO (2014a, p. 45), 'YLL due to premature mortality are calculated from the number of deaths at each age multiplied by a global standard life expectancy of the age at which death occurs'.

how the phenomenon is termed, however, data consistently shows that the numbers of people living with more than one chronic condition outnumber those living with one chronic condition (Jadad et al., 2010; Barnett et al., 2012; DH, 2012; WHO, 2014a). In Wales, for example, comorbidity is reported by a third of all people who report living with a chronic condition (NPHSW/WAG, 2006). The existence of multiple chronic conditions is associated with worse health outcomes such as poorer health-related quality of life and higher mortality, whilst people living with multimorbidity are higher users of care than those without (see, for instance, Gijsen et al., 2001; Wolff et al., 2002; Fortin et al., 2004; 2007; Kadam et al., 2007; Lee et al., 2007; Perruccio et al., 2007; Commonwealth Fund, 2010).

Arguably, the global scale of the issue of chronic conditions is nowhere more clearly illustrated than in the opening paragraph of the draft political resolution of the 2011 High-Level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases:

> We, Heads of State and Government and representatives of States and Governments, assembled at the United Nations from 19 to 20 September 2011, to address the prevention and control of non-communicable diseases worldwide, with a particular focus on developmental and other challenges and social and economic impacts, particularly for developing countries,
>
> 1. Acknowledge that the global burden and threat of non-communicable diseases constitutes one of the major challenges for development in the twenty-first century (United Nations General Assembly, 2011, p. 1).

There are correlations between long-term ill-health and socio-economic factors such as deprivation, income-disparity and lifestyle ,which mean that increasing numbers of people of all ages – including children and young people – are developing chronic conditions (see, for instance, Pomerleau et al., 2008; van Cleave et al., 2010; Global Alliance for Chronic Diseases [GACD], 2012; WHO, 2014). But it is widely recognised that a major contributory factor to the epidemiological transition is demographic change and increased longevity (see, for instance, Carrier, 2009; WHO, 2011; 2014a; Barnett et al., 2012; DH, 2012; Nolte et al., 2012; PRB, 2012; Goodwin et al., 2014). The reason for this is that physiological changes that occur as people grow older increase their risk of developing one or more chronic condition

(s) (see DH, 2010; 2012; Barnett et al., 2012; PRB, 2012; Coulter et al., 2013; Oliver et al., 2014; WHO, 2014a).

The NIA/NIH/USDHHS/WHO (2011) reports that among the world's population of people aged sixty and over, NCDs account for more than eighty-seven percent of the disease burden. Indeed, the WHO (2011) reports that a quarter of the global population of sixty-five to sixty-nine year-olds is living with more than one chronic condition, a figure that rises to half of people aged between eighty and eighty-four. Fifty-eight percent of people aged sixty and over report living with at least one chronic condition in England (DH, 2012), with two thirds of people aged over sixty-five reporting living with at least one chronic condition in Wales (National Public Health Service for Wales [NPHSW]/Welsh Assembly Government [WAG], 2006).

Moreover, there is a strong association between ageing and the existence of multimorbidity (see van den Akker et al., 1998; Vogeli et al., 2007; Walker, 2007; Marengoni et al., 2011; Salisbury et al., 2011; Barnett et al., 2012; Banerjee, 2015). Although exact figures are contested (Pomerleau et al., 2008), studies from across the world consistently show that more than fifty percent of older people are living with multimorbidity (Marengoni et al., 2011). In some parts of Europe, for instance, two thirds of people of pensionable age report living with at least two chronic conditions (van den Akker et al., 1998; Wolff et al., 2002) and in Wales, half of people aged between eighty and eighty-four and three-quarters of people aged over eighty-five report having a limiting long-term illness (NPHSW/WAG, 2006). In the next section I describe the impact these factors are having on the world's health and social care systems.

Health and social care systems under pressure: the need for change

In the previous section, I drew attention to the global impact of demographic change and the associated epidemiological transition and increase in the numbers of people living with chronic conditions. With thirty-eight million (sixty-eight percent) of the world's fifty-six million fatalities in 2012 attributable to NCDs (WHO, 2014) it is widely recognised that the burden of chronic conditions is assuming ever more magnitude, with chronic illness set to affect an increasing proportion of the world's

population in coming years (see, for instance, Mathers and Loncar, 2006; WHO, 2010; 2014; NIA/NIH/USDHHS/WHO, 2011; Global Burden of Disease Mortality and Causes of Death Collaborators, 2015).

Many commentators point out that the repercussions of these changes for the organisation of health and social care systems worldwide are far-reaching (see, for instance, Carrier, 2009; Wellard, 2010; Goodwin et al., 2014; Oliver et al., 2014). There are numerous reports, for instance, that the financial and human resources required to meet the complex needs of people living with chronic conditions are impacting on many aspects of service provision, with the growth in numbers of older people greatly increasing the burden on national economies worldwide (see, for instance, Suhrcke et al., 2006; 2008; Pomerleau et al., 2008; Busse et al., 2010; Nolte et al., 2012; Nolte and Pitchforth, 2014). According to Nolte et al. (2012) whilst these challenges require effective measures to prevent disease – for instance, by reducing risk factors and addressing the influences that drive exposure – they also call for the development of services that better meet the requirements of people living with chronic health problems.

With countries throughout the world facing analogous pressures (see Suhrcke et al. 2006; 2008; Carrier, 2009; Legido-Quigley et al., 2013; Nolte and Pitchforth, 2014) the UK has not escaped this trend (see Carrier, 2009; Coulter et al., 2013; Goodwin et al., 2014; Oliver et al., 2014). On the contrary, the DH (2012) reports that the increasing numbers of people living with chronic conditions are placing considerable and growing demands on numerous levels of care provision, from community services to emergency care and acute hospital services. The DH (2012, p. 3) reports that in England, for instance, people living with chronic conditions account for: half of all General Practitioner (GP) appointments; sixty-four percent of all outpatient appointments and seventy percent of all inpatient bed days. Moreover, with the DH (2012, p. 10) stressing that people living with LTCs are, 'the most intensive users of the most expensive services', it also notes that seventy percent of the entire health and care spend in England is given over to providing care for people living with chronic conditions, a disproportionately high level given that they constitute thirty percent of the population.

Moreover, the WAO (2014) warns that given the projected rise in the population of people aged sixty-five and over in Wales in coming years, the prevalence of chronic conditions is likely to place an ever-increasing burden on Welsh health and social care services. At the same time, however, the austerity measures of the Conservative/Liberal Democrat Coalition Government, whilst less far-reaching than some areas of the UK, have seen a real-term reduction in central government funding for Welsh councils (WAO, 2011).

But amidst growing pressures on health and social care systems around the globe, it is argued that many of these systems are ill-suited to meeting the care needs of people living with chronic conditions, with the need to develop a system-wide model of chronic conditions care remaining (see, for instance, WHO, 2011; 2014; Nolte and Pitchforth, 2014; 2014a). In order to understand why this is, it is first of all important to understand the all-pervasive impact of living with chronic illness (see, for instance, MacKay and Mensah, 2004; Nolte et al., 2008; Novotny, 2008; Busse et al., 2010; Coulter et al., 2013). Carrier (2009) notes that this affects not only physical health – resulting, for instance, in the need for increased visits to the hospital and GP and periods of rehabilitative care from allied health professionals (such as occupational therapists and physiotherapists) – but also has implications for countless other aspects of day-to-day life.

Hence, Carrier (2009) explains that chronic conditions are often associated with a range of complex psychological and psychosocial issues, affecting family relationships, everyday socialisation and the ability to go to work or school and to take care of one's daily physical needs. Moore (2008), however, reports that most health care systems in the world – including the UK's National Health Service (NHS) – are still based upon the biomedical model of health. According to the latter:

> Health is the absence of biological abnormality; diseases have specific causes; the human body is likened to a machine to be restored to health through personalised treatments that arrest, or reverse, the disease process; the health of a society is seen as largely dependent on the state of medical knowledge and the availability of medical resources (Taylor, S., 2003, pp. 21 – 22).

In Wales, demands on the NHS are also increasing, as the many indirect and direct resources associated with providing care for people living with chronic conditions impact on both the health and wellbeing of individuals and the primary, secondary and social care services that support them (NPHSW/WAG, 2006; WAO, 2014). But given the widespread recognition that people living with chronic conditions have complex care needs which span a range of health and social care services (see, for instance, WAG, 2007; Williams and Sullivan, 2009f; Carrier, 2009; Busse et al., 2010) it has been argued that it is critical to understand the social influences on health of those living with chronic conditions (Carrier, 2009) and that their care should instead be rooted in the *social* model of disability (Denny and Earle, 2009). According to the latter, the problems experienced by people living with disabilities result from their 'physical, social and attidudinal [*sic*] environments' (Locker, 2003, p. 84). Denny and Earle (2009) explain that the social model regards disability as a societal issue – with disabled people (including those living with chronic conditions) handicapped not by their impairments, but by societal structures – and recognises the need for self-determination and autonomy.

However, with Ellins and Coulter (2005) explaining that in the traditional biomedical model of healthcare delivery, the patient is viewed as a passive recipient of medical expertise, services and treatments, Brown and Piper (1995) add that the roles of expert health care professional and novice client are ill-suited to chronic conditions, with the latter's long-term and all-pervasive nature seeing the expertise of the health care professional often reduced compared to that of the person living with the chronic condition. Accordingly, note, Paterson and Sloan (1994) whilst the former tends to understand chronic conditions in general terms, the latter normally understands the vagaries of his or her circumstances in a far more sophisticated manner.

This is perhaps unsurprising, given that people living with chronic conditions do so for twenty-four hours a day, 365 days a year, and that during a year they may only interact with health care professionals for just a few hours (see, DH, 2004; Coulter, 2012). As a consequence, people living with chronic conditions are responsible for caring for themselves for most of the time (see, for instance, Holman and Lorig, 2000; Thorne et al., 2003; DH, 2004; Carrier, 2009; Coulter, 2011; Coulter et al.,

2013). Seminal to the day-to-day existence of people living with chronic conditions, therefore, are self-care and self-management (Alabaster, 2006; Long Term Alliance Scotland, 2008; Carrier, 2009; Coulter, 2011; Coulter et al., 2013). The former is defined by Orem (1991, p. 117) as, 'the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being'. The latter, according to the Long-Term Conditions Alliance Scotland (2008, p. 12) is,

> ... a concept where the person takes ownership and is central. It is a process of becoming empowered to manage life with long term conditions. It is not an individual action, a specific treatment or service; neither can it be delivered by a single organisation. Self management is the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition.

Epping-Jordan et al. (2004, p. 304) draw attention to a growing body of evidence that shows that people living with chronic conditions benefit from receiving treatment, 'within an integrated system with self-management support'. In a similar vein, Greene and Hibbard (2012, p. 520) point out that people living with chronic conditions experience better outcomes when they are adequately 'informed and activated'; this means, the researchers explain, that they have the requisite, 'motivation, knowledge, skills, and confidence to make effective decisions to manage their health' (2012, p. 520).

Coulter (2007) explains that in England and Wales, the cornerstone of governmental efforts to promote self-management has been the Expert Patient Programme (EPP). The latter is a lay-led self-management programme designed for people living with LTCs with its foundations, in the United States (U.S.), in the Chronic Disease Self-Management Programme (Lorig et al., 1999). Carrier (2009) notes that the EPP was launched in Wales[8] in 2002, with the Welsh Government demonstrating a firm commitment to the programme's Wales-wide roll-out. In Chapter Four, 'Setting the context for the case study', I describe how the network of services in Armorshire for people living with chronic conditions that pre-dated the launch of the National CCM

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[8] In Wales, the EPP is known as the Education Programme for Patients, see http://www.wales.nhs.uk/sites3/home.cfm?orgid=537

Demonstrator Programme included the EPP and the X-PERT Programme[9], the latter tailored to meet the needs of people living with type 2 diabetes.

Bandura (1995) notes that the development of the EPP drew upon self-efficacy theory – based on the premise that clients who feel confident in managing their condition will be able to exercise control in doing so (Williams and Bond, 2002) – and has sought to increase client empowerment. The latter, explains Laverack (2007, pp. 13 – 14), 'in the broadest sense is seen as a process by which people work together to increase control over events that influence their lives'. According to Means et al. (2008) empowerment concerns the direct involvement of clients in decisions affecting their welfare, with Barnes and Bowl (2001, p. 18) noting that in the context of social policy and health and social care practice, empowerment has often been conceptualised in terms of, 'a shift in the nature of the relationship between those who provide and those who receive services'.

According to Beresford and Branfield (2006), empowerment is based on involvement, respect, choice, equality and the valuing of diversity as part of broader issues of human and civil rights. Gibson (1991) notes that this has implications for the partnerships between health and social care professionals and their clients, drawing attention to the responsibility of health care professionals to facilitate empowerment by supporting clients in meeting their own needs, in problem solving, and in arranging the necessary resources to take control of their lives.

Arguing that empowerment is central to improving the management of care of people living with chronic conditions, Coulter et al. (2013) add that this care management should be proactive, holistic, preventive and patient-centred, with an active role for patients based on collaborative personalised care planning. Coulter et al. (2013) explain that this means that health care professionals need to abandon traditional ways of thinking and behaving – whereby they view themselves as the primary decision-makers – and to adopt a partnership model in which patients play an active part in determining their own care and support needs. Coulter et al. (2013) explain that this process of involvement sees people living with chronic conditions

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[9] Information at: http://www.xperthealth.org.uk/people-with-diabetes/x-pert-diabetes

deciding on their own priorities by way of information-sharing and joint decision-making but supported to do so by health and social care professionals.

Indeed, with Holman and Lorig (2000, p. 526) indicating that the delivery of health care is more effective and efficient if service users are actively involved, they stress that people living with chronic conditions must therefore, 'become a partner in the process, contributing at almost every decision- or action-level'. In a similar vein, Bodenheimer et al. (2002a) note that self-management is premised upon collaboration, with clients viewed as experts in their own lives, and health care professionals as experts in diseases. Rees and Williams (2009) point out that it is therefore important that health care professionals recognise patient knowledge and expertise, with Bodenheimer et al. (2002) suggesting that optimum care for chronic illness occurs when a prepared, proactive practice team interacts with an informed, activated patient. However, Coulter et al. (2013) argue that despite widespread recognition of need for a radical re-design of services for people living with chronic conditions in the NHS whereby patients drive the care planning process by means of greater involvement, little improvement has thus far been achieved.

Once again, however, there is little consensus as to the precise meaning of the term 'involvement' (Baggott, 2005; Beresford, 2012). But this is perhaps in keeping with a phenomenon which, note Barnes and Wistow (1992), can take many different forms, including consulting, information-giving, establishing consumer satisfaction and participating in decision making. Barnes and Wistow (1992, p. 4) point out, however, that involvement activities usually fall under one of 'two broad categories of purpose', namely: 'those which seek to improve the quality of services by making them more sensitive or more responsive to the needs and preferences of those who use them' and, 'those which seek to extend the capacity of users to participate in decisions about the design, management and review of services'.

I revisit these issues in Chapter Two, 'Integration and the management of chronic conditions: a review of the literature', when I explore patient and public involvement (PPI) initiatives. But in addition to a change in the relationships between health and social care professionals and service users, the all-pervasive nature of living with chronic conditions has other implications in terms of the organisation of health and

social care systems. Alabaster (2006), for instance, draws attention to the wide range of services required by people living with chronic conditions and the considerable expense this can incur. Alabaster (2006) explains that these factors can be understood in terms of the long-term nature of support – with the need for ongoing and repeated contact with a range of agencies – and of the increase in intensity of this support should people's conditions deteriorate. Like Carrier (2009), Alabaster (2006) emphasises that people living with chronic conditions require support from a variety of (allied) health care and social care professionals, including therapists, nurses, doctors, social workers and social care professionals.

The need for the latter's involvement arises, explain Goodwin et al. (2014), because people living with chronic conditions (particularly those who are older) often require support with everyday activities such as dressing, bathing, shopping or preparing food. Indeed, with Twigg (1998) noting that the long-term nature of the care required by people living with chronic conditions means that it falls across care boundaries, Kodner (2006) adds that in both community and institutional settings, people living with chronic conditions often require services delivered by a range of health care *and* social care professionals. Billings et al. (2013, p. 7), moreover, point out that since they cannot be 'cured', people living with long term conditions fall outside the traditional medical binary-code of 'well versus ill'. Accordingly, Grumbach (2003) indicates that the goal of chronic care is to enhance functional status, minimise distressing symptoms and to prolong life and to enhance its quality.

With this in mind, Billings et al. (2013, p. 7) indicate that people living with chronic conditions require, 'care, assistance, social support and rehabilitation to accomplish instrumental activities of daily life'. Billings et al. (2013, p. 7) hasten to add, however, that these are functions for which health care systems are, 'poorly organised'. With these comments chiming with Nolte et al.'s (2008) indication that most countries' care systems are ill-equipped to meet the needs of people living with chronic conditions, Nolte et al. (2008) explain that one of the underlying reasons for this is that most were not designed for chronic conditions, but for acute diseases. In order to understand why this is, it is helpful to understand some of the key differences between acute disease and chronic illness. These are set out in Table 1 (see overleaf).

Table 1: Features of Acute Disease and Chronic Illness (source, DH, 2004b, p. 8).

	Acute disease	Chronic illness
Onset	Abrupt	Generally gradual and often insidious
Duration	Limited	Lengthy and indefinite
Cause	Usually single	Usually multiple and changes over time
Diagnosis and prognosis	Usually accurate	Often uncertain
Technological intervention	Usually effective	Often indecisive; adverse effects common
Outcome	Cure possible	No cure
Uncertainty	Minimal	Pervasive
Knowledge	Professionals knowledgeable, patients inexperienced	Professionals and patients have complementary knowledge and experiences

Nolte et al. (2008) explain that since most health care systems were designed with acute conditions in mind, most are based on an acute and episodic model of care. The latter, explains the WHO (2002), is characterised by testing, diagnosing, and relieving symptoms, is based on the expectation that a cure will be found, and frequently sees expert health care professionals providing specialist (and disease-specific) care to people who have little knowledge of their presenting disease (see also Holman and Lorig, 2000). Accordingly, adds the WHO (2002), it is a model that is not appropriate for the complex needs of people living with chronic

conditions. These are people who require holistic[10] care from a broad range of health *and* social care professionals, but who also – given that for most of the time they are responsible for meeting their own needs – have considerable expertise in their own condition(s) and therefore should be viewed as equal partners in care (see also DH, 2004b; Holman and Lorig, 2000; Goodwin et al., 2012; 2014; Coulter, 2011; Coulter et al., 2013).

But with the WHO (2002, p. 4) arguing that the rise in prevalence of chronic conditions has led to a, 'mismatch between health problems and health care', it attributes this discrepancy to the fact that most existing care systems in the world pre-date the epidemiological transition, when the burden of acute disease outweighed that of chronic conditions. Despite the subsequent reversal of this situation, the WHO (2002) states that most care systems have not, to any great extent, evolved beyond the conceptual approach used in diagnosing and treating acute conditions, with the acute care paradigm continuing to permeate all levels of care. But with the NHS likewise designed prior to the epidemiological transition, it too remains rooted in the acute and episodic model of care and, like much of the world, its health and social care systems have failed to keep up with demographic and epidemiological change (see National Voices, 2011; Coulter et al., 2013; Goodwin et al., 2014; Oliver et al., 2014; Naylor et al., 2015).

But alongside the pre-eminence of the acute and episodic model of care, other factors also militate against the effective care of people living with chronic conditions, such as the separate development of the organisation of health care and social care systems (Goodwin et al., 2012). Thus, Leichsenring (2003) points out that the majority of European countries, for example, have separate ministries for health affairs and social affairs and a marked difference in the handling of health care issues and social care issues. Whilst Leichsenring (2003) explains that the former are usually regulated by a national health system or national insurance system, he adds that the latter are often administered by regional or local social assistance systems.

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[10] Holistic care, 'considers a person as a whole and respects their social, spiritual, mental and physical health needs rather than focusing on one or some aspect/s' (Williamson et al., 2006, p. 148).

Lloyd and Wait (2005) note, furthermore, that access to health care is often defined differently from access to social care, with healthcare coverage often universal or quasi-universal, and social care normally means-tested. Most of the UK, with the exception of Northern Ireland, shares this demarcation between the provision of health care services and social care services (see, for instance, Heenan, 2013; Longley, 2013; Steel, 2013; Goodwin et al., 2014). Accordingly, those considered sick are viewed as having health care needs to be met by the NHS (a national body) and given free at the point of delivery, but those considered frail or disabled are viewed as having social care needs that fall under the remit of the local authority and are means-tested (see, for example, Means et al., 2008; Ham, 2009a; Glasby, 2012). As a reflection of the disease-specific nature of the acute and episodic model of care and the separate development of health and social care systems, Nolte and McKee (2008) explain that many health and social care professionals have traditionally worked separately, with providers traditionally located in different settings. Nies (2009), in turn, describes the isolated development of different care systems in terms of funding, legislation, organisation, culture and working practices.

But Jelphs and Dickinson (2008) also point out that recent years have seen the progressive replacement of generalist health and social care posts with a diverse range of occupations and specialisms that are focused on a particular field of work, problem area or client group. Whilst Jelphs and Dickinson (2008) explain that such specialisation means that individual professionals have greater understanding of specific problems, they add that since it is unlikely that their knowledge of their own profession (or others) is exhaustive, it has also increased the need to work with a wider range of colleagues internal to their organisation. Hence, at the same time that the growing numbers of people living with chronic conditions – whose needs are multifarious – have increased the need for the involvement of a range of agencies, the agencies themselves have become more internally fragmented.

Indeed, with Glasby et al. (2006) also drawing attention to the structural and financial barriers which divide providers at the interfaces of primary and secondary care and of health and social care, to the barriers created by distinct organisational and professional cultures, and to differences in governance and accountability, they argue that the entire development of service delivery has resulted in the

fragmentation of care (both within and between sectors). But according to the Pan American Health Organization/World Health Organization (PAHO/WHO) (2011) such fragmentation has multiple repercussions in terms of the care of people living with chronic conditions. These include: a lack of co-ordination between different levels of care and care settings; duplication of services and infrastructure; unutilised productive capacity; care provision at the least appropriate location (especially hospitals); the use of emergency services (instead of outpatient services) for specialised care; unnecessary hospitalisation of patients; unnecessary extended hospital stays; lack of access to services; lack of continuity of care; and the failure of services to meet users' needs. Edwards (2014, p. 3) explains that in the NHS, fragmentation of care means that:

> A pattern of large numbers of small, narrowly defined and often poorly co-ordinated services (usually delivered by different providers) has arisen, making the system difficult to understand and navigate, even for professionals. This has mainly been the result of services being created for a particular purpose or client group without a clear plan for how they relate to the wider system. The fragmentation of services and tasks means that patients receive multiple visits from different professionals, incurring high costs of co-ordination, and leading to frustration for the referring clinicians, their patients and carers.

So, amidst widespread recognition that the care of people living with chronic conditions should be proactive, holistic, co-ordinated and consistent, there are numerous reports that throughout the world (including the UK) the delivery of care – still based on the acute and episodic model and with a distinct demarcation between health and social care systems – is often characterised by fragmentation and concomitant gaps in provision, duplication and a lack of care-continuity (see, for instance, McDonald et al., 2007; Nolte and McKee, 2008a; Minkman et al., 2009; Commonwealth Fund, 2010a; Nolte et al., 2012a; Coulter et al., 2013; Goodwin et al., 2014; Oliver et al., 2014; Naylor et al., 2015).

Accordingly, it is argued that health ministries and policy-makers worldwide need to develop and implement[11] specific policies and interventions so that the complex and multiple needs of the burgeoning numbers of (older) people living with chronic

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[11] Implementation, according to Fixsen et al. (2005, p. 5) refers to a, 'specified set of activities designed to put into practice an activity or program of known dimensions'.

conditions are better met (see, for instance, Nolte et al., 2008; WHO, 2014). Indeed, the WHO (2002) stresses that patients, care professionals and decision-makers must recognise that effective chronic conditions care requires the development of an entirely different kind of health care system as a part of a 'paradigm shift'. In the words of Wellard (2010, p. 8): 'The global challenge is increasingly clear. There is a need for radical shifts in the way health is managed to address the impact of the epidemic of chronic illness.'

In the next section I discuss some of the efforts that have been made to improve systems of care for people living with chronic conditions. I consider one concept that has been widely used in the context of the care people living with chronic conditions, disease management, before introducing a second concept – and the one which underpinned the development of the new CCM service in the Welsh locality of Bro-y-Grug – integrated care.

Improving the care of people living with chronic conditions: the importance of integration

In the previous section, I explained that amidst mounting pressures on health and social care services worldwide, there is widespread recognition that existing care systems are ill-suited to meeting the complex needs of people living with chronic conditions. Accordingly, I added, the reorganisation of these care systems has become a matter of international concern. Whilst the WHO (2014, p. xii) notes that the need to address this issue is pressing in all nations, it points out that since each is at a different stage in its progress towards the 'prevention and control' of NCDs, there is, 'no single pathway' that should be followed to bring about change. On the contrary, recognising that the wide variety of care systems precludes a uniform response, Nolte et al. (2008, p. 2) suggest that in order to improve care services for people living with chronic conditions, different governments, 'must find their own solution'.

Nolte and Pitchforth (2014a), however, note that in seeking to identify effective approaches to improving systems of care for people living with chronic conditions, the absence of common definitions of underlying concepts is a significant issue. Indeed, there is widespread recognition that the field of chronic conditions care is

terminologically challenging, with regular use of a multitude of terms such as coordinated care, collaborative care, managed care, (chronic) disease management, case management, patient-centred care, chronic (illness) care, continuity of care, integration and integrated care (see, for instance, Nolte and McKee, 2008; McDonald et al., 2007).

Despite the fact that many of the terms that are regularly used may differ conceptually, a lack of definitional and semantic consensus means they are frequently used interchangeably, thereby leading to a blurring of the boundaries between them (Kodner and Spreeuwenberg, 2002). According to Nolte and McKee (2008), this multitude of terms (and of concepts) – and lack of agreement on definitions and meanings – is a reflection of the range of disciplines and professionals – and concomitant range in perspectives – typically called on in the care of people living with chronic conditions. But Nolte and Pitchforth (2014a) argue that this has significant implications for practice and learning, with the resultant lack of clarity as to what a term or concept consists of or entails militating against the comparison of empirical evidence, and in turn, against the drawing of conclusions *vis-à-vis* the relative value of different approaches.

Notwithstanding, Nolte and Pitchforth (2014a, p. 10) point out that two concepts that are frequently used in the context of systems of care for people living with chronic conditions are 'disease management' and 'integrated care'. Prior to turning my attention to integrated care – the concept upon which the new CCM service in Bro-y-Grug was built – I briefly discuss disease management, a concept that was first described in the United States of the 1980s in the context of educational programmes promoting medication adherence and behaviour change for people living with specific chronic conditions (see Bodenheimer, 1999). According to Faxon et al. (2004, p. 2652), disease management, 'typically refers to multidisciplinary efforts to improve the quality and cost effectiveness of care for selected patients suffering from chronic conditions'. Nolte and Hinrichs (2012, p. 4) note that disease management often includes the following components:

      (a) collaborative models of care among providers such as physicians,

hospitals, laboratories and pharmacies; (b) patient education; and (c) monitoring/collection of patient outcomes data for the early detection of potential complications.

However, there is little agreement on the definition, meaning or conceptual basis of disease management, with a concomitant lack in terminological consistency (see Krumholz et al., 2006; Goodwin, 2007; McDonald et al., 2007; Peytremann-Bridevaux and Burnard, 2009; Schrijvers, 2009; Nolte et al., 2012). For instance, the term chronic disease management is also widely used, defined by the Royal College of Physicians/Royal College of General Practitioners/NHS Alliance ([RCP/RGP/NHS Alliance], 2004, p. 1) as, 'a system of co-ordinated health interventions and communications for populations with chronic conditions in which patient self care is significant'. (During my research, I was unable to find a definition of 'chronic conditions management'. However, it appears to be used interchangeably with [chronic] disease management). On the contrary – and incorporating a range of interventions and target populations – descriptions of disease management and approaches to its implementation are many and diverse (see Coleman et al., 2009; Goodwin, 2007; Lemmens et al., 2009; Pimouguet et al., 2011; Nolte and Hinrichs, 2012; Nolte and Pitchforth, 2014a). Hence, some fifty different strategies – in just twelve countries – are noted by Nolte and Pitchforth (2014a) in their overview of disease management in Europe.

Following widespread utilisation in U.S. care systems in the 1990s (Krumholz et al., 2006) disease management strategies have been adopted in other parts of the world, including Australia, Canada, as well as Europe (see, for instance, Glasgow et al., 2008; Jiwani and Dubois, 2008; Hewison and Cox, 2009; Nolte and Hinrichs, 2012; Nolte and Pitchforth, 2014a; Rijken et al., 2014). Despite its popularity, given that the focus of disease management in many settings is on single diseases (see Nolte et al., 2012), concerns have emerged regarding its suitability to address the complex needs of people living with multiple disease processes (Aspin et al., 2010; Nolte et al., 2012a; Rijken et al., 2014).

In addition to the implementation of different systems of disease management, many governments' efforts to improve the care of people living with chronic conditions have involved the integration of health and social care (Nolte and McKee, 2008;

Billings et al., 2013; Goodwin et al., 2014; Nolte and Knai, 2014a). Kodner and Spreeuwenberg (2002, p. 3) define integration in the context of health and social care as:

> ... a coherent set of methods and models of the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors.

As with disease management, however, there is little agreement on the definition, meaning or conceptual basis of integration, with a concomitant lack of terminological consistency and sound conceptual framework by which it can be analysed (see, for instance, Goodwin et al., 2004; 2012; MacAdam, 2008; Curry and Ham, 2010; Ham and Curry, 2011; Nolte and Pitchforth, 2014; 2014a). I explore these issues in detail in Chapter Two, when I discuss how numerous terms – such as integration, integrated care, partnership (working), collaboration, joint-working, alliance, coalition, cooperative and merger – are employed in such a way that their meanings and the differences between them are unclear.

Nolte and McKee (2008, p. 65) point out, however, that the wide variety of terms used in the field of integration is a reflection of the 'polymorphous nature of a concept that is applied from several disciplinary and professional perspectives and is associated with diverse objectives', with Goodwin et al. (2014, p. 2) suggesting that this means that integrated care, 'can mean different things in different settings'. But just as I have referred to Nolte and Pitchforth's (2014a) contention that a lack of definitional and conceptual consensus across the entire field of chronic conditions care has militated against its overall development, so in Chapter Two I explore how a lack of common understanding of the meaning and purpose of integration has also adversely affected the development of this particular aspect of chronic conditions care.

Nevertheless, there is widespread belief that integration can help address the discrepancies between existing models and systems of service delivery and the needs of people living with chronic conditions (see, for instance, Goodwin et al., 2012; 2014; Nolte and Knai, 2014a; Naylor et al., 2015). As I explained in the previous section, the main problems that have been identified are: the pre-eminence of a

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biomedical model in which people with chronic conditions are not adequately involved; the existence of health care systems that were, in the main, designed according to an acute and episodic model of care and which are ill-suited to meeting the needs of people living with chronic conditions; the divisions between health and social care systems and the separate and isolated development of different sectors of care and concomitant fragmentation of services.

Whilst in Chapter Two I explore why it is felt that these issues can be solved by integration, that this belief is widely shared is evidenced by the numerous reports of different countries' implementation of integrative measures in chronic conditions care (see, for instance, Conrad and Shortell, 1996; Ouwens et al., 2005; Hébert et al., 2008; Kodner, 2009a; Ham et al., 2011; Goodwin et al., 2012). Goodwin et al. (2014) point out that integrated health and social care programmes for older people living with complex needs are currently used, *inter alia*, in Australia, Canada, the Netherlands, New Zealand, the United States and the UK.

As regards the latter, it is argued that the growing interest in different forms of integrated working of recent years reflects the historic divisions between health and social care services to which I referred in the previous section (see Lymbery, 2005; Means et al., 2008; Baggott, 2013). Indeed, systematic incorporation of various forms of partnership-working into many areas of government policy began as long ago as 1997 with the UK general election victory of New Labour, with the latter's 'Third Way' proposing a system of governance to be accompanied by an explicit statement of partnership goals (Dowling et al., 2004). Whilst the years following New Labour's victory saw UK legislation and guidelines place an increasing emphasis on partnership, interest in different forms of joined-up working does not appear to have diminished since this time. On the contrary, Heenan (2013, p. 2) notes that integration, 'has been an explicit policy goal of successive UK governments over the last two decades'.

Although the UK, just like many other parts of the world, is looking to greater integration of health and social care to join up fragmented health and social care systems, there is limited, uncertain and inconclusive evidence to show that integrated

working is effective (Nolte and McKee, 2008). In terms of the outcomes[12] for people receiving health and social care (including those living with chronic conditions), the evidence-base that integration leads to improvements is far from conclusive, as is the evidence that service user involvement in the design and delivery of services has increased (see, for instance, Barnes and Coelho, 2009; Dickinson, 2009; Shaw et al., 2011; Cameron et al., 2012; Renedo and Marston, 2011; Mockford et al., 2012; Dalton et al., 2014). This, despite the fact that a number of commentators agree that the 'organising principle' of integrated working should be the service user perspective (Shaw et al., 2011; Goodwin et al., 2012) and that the 'common demoninator' of integration is the improvement of care of service users (Øvretveit, 1998; Billings et al., 2013; Coulter et al., 2013).

But with little evidence that integration improves care for people living with chronic conditions or that there has been significant involvement of service users in the design and delivery of services, in this thesis I attempt to address these issues by using a case study approach that incorporates multiple stakeholder perspectives – including those of people living with chronic conditions and their carers – from an interpretevist standpoint. I examine in more detail the lack of evidence that shows that integrated working benefits service users or that the latter have been involved in the design and delivery of new services in Chapter Two, and my use of the case study approach, methods of data collection (and analysis) and interpretevist stance in Chapter Three, 'Methodology and methods'. In the next section of this chapter, however, I describe how Wales has also looked to incorporate integrated working into a new model of care for people living with chronic conditions, the Welsh CCM Model.

The Welsh CCM Model: integration, self-management, involvement, empowerment

Sullivan (2004) notes that prior to devolution, Wales – along with the other devolved countries of the UK – had a distinct way of adapting (health) policy and delivering services, but that differentiations have sharpened since the formation of the Welsh Assembly. Indeed, according to Greer (2005, p. 508) Wales offers, 'the most

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[12] Burke et al. (2012, p. 20) define 'outcome' as, 'the changes for service users, citizens, or other targets of change that happen as a result of an innovation being provided'.

striking case of policy and political change since devolution', with health service reorganisation in Wales designed to shift the, 'centre of gravity of the health service downward and better integrate local government and health services' (2005, p. 509). According to Birrell (2009) the post-devolution era in Wales has been characterised by the principles of citizenship, public involvement, mutualism, localism and partnership-working, with Williams and Sullivan (2009, p. 6) likewise noting that 'partnership' is a 'key element' of Wales' prevailing model of public service. In a similar vein, Sullivan and Drakeford (2011) note that post-devolution, the NHS in Wales has entrenched an ethos of localism, with an emphasis on partnerships between health, local government and the voluntary/third sector.

Whilst indicating that there is no single Welsh Government document that is devoted to integrated care, Longley (2013, p. 63) points out that, 'aspects of the concept appear in many policy documents'. Alongside *Our Healthy Future* (WAG, 2009), Longley (2013) draws particular attention to two documents which were of central importance to this case study. These were: *Setting the Direction: Primary and Community Services Strategic Delivery Programme* (WAG, 2010; henceforth *Setting the Direction*) and *Designed to Improve Health and the Management of Chronic Conditions in Wales: An integrated model and framework* (WAG, 2007; henceforth *Designed to Improve Health and CCM in Wales*). As for the former, in Chapter Six, 'Flux, ambiguity and time-pressures: the impact on the Armorshire Collaboration', I explain how the belated introduction of one of its main features – the Community Resource Team (CRT) – resulted in a degree of ambiguity *vis-à-vis* the project's aims (and therefore adversely affected the delivery of an integrated CCM service in the Bro-y-Grug locality). As for the latter, this was of central importance to this case study, given that it was in this document that the Welsh Government set out its goals for the management of care of people living with chronic conditions by way of a new integrated model.

Originally called the 'Integrated Model and Framework' (WAG, 2007) the model has also been called, *inter alia*, the 'Welsh Chronic Conditions Model' (WAG, 2008), the 'CCM Model' (WAG, 2009a) and the 'Welsh CCM Model and Framework' (WAG, 2008b; I mostly use the term 'Welsh CCM Model' in this case study). It was indicated in *Designed to Improve Health and CCM in Wales* (WAG,

2007) that the Welsh CCM Model comprised three core themes: the recognition that chronic conditions impact on all areas of life; the promotion of strong partnerships between social and health care agencies, the voluntary/third sector and clients and carers; and the empowerment of clients and carers and their active participation in systems of care. It was also explained that the Welsh CCM Model would use population stratification and split care into four levels of ascending degrees of health and social care intervention according to need, as set out in Figure 1 (see under).

Figure 1: The Welsh CCM Model (as set out in *Designed to Improve Health and CCM in Wales* [WAG, 2007, p. 19])

Figure 4: The Welsh Chronic Conditions Model
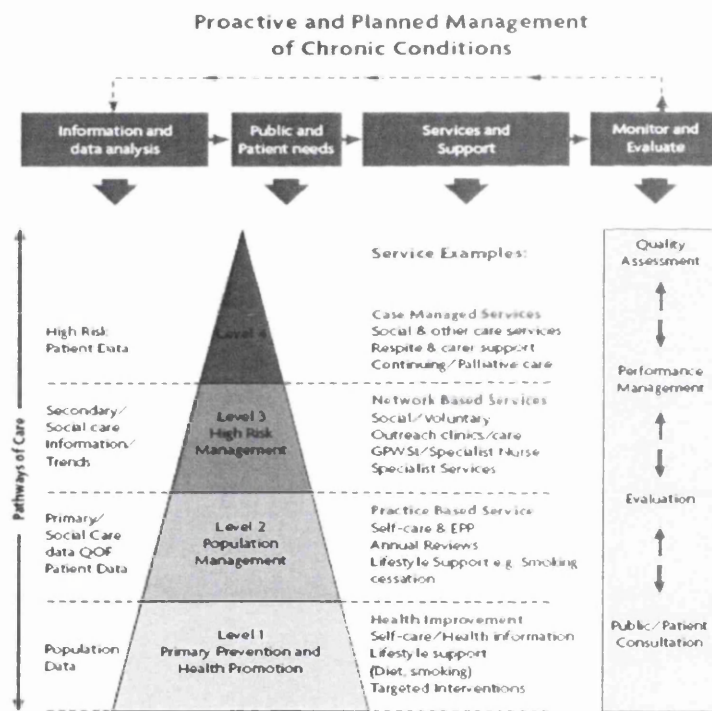
In *Designed to Improve Health and CCM in Wales* (WAG, 2007) it was explained that the designers of the Welsh CCM Model had drawn on evidence and developments outlined in the earlier Welsh Government document, *International Overview of the Evidence on Effective Service Models in Chronic Disease Management* (WAG, 2006). One of the latter document's key messages was that the quality of care of people living with chronic conditions could be improved by CCM programmes based on the Chronic Care Model (see Wagner et al., 2001). The latter,

in turn, is premised on transforming health care for people with long-term conditions from a predominately reactive system (that responds when people are ill) to an increasingly proactive system that focuses on facilitating self-management (Wagner, 1998).

With the indication, in *Designed to Improve Health and CCM in Wales* (WAG, 2007) that a, 'large proportion of care for people living with chronic conditions is provided through self-care by individuals, their carers and local communities' (2007, p. 28) it was explained that one of the 'foundations for change' of the Welsh CCM Model would be 'independence and self-care' (2007, p. 28) and that it would incorporate EPPs for those identified as being at the 'population management level' (WAG, 2007, p. 19). In the *Service Improvement Plan* (WAG, 2008) it was further noted that self-management programmes would help to, 'maintain independence and ability to self-care' and that self-management training and education would be 'incorporated into interactions between the patient and health and social care staff' (WAG, 2008, p. 31).

It was also indicated in *Designed to Improve Health and CCM in Wales* (WAG, 2007) that a core principle of the Welsh CCM Model was that local people, people living with chronic conditions and their carers would have involvement in the design and delivery of CCM services. With the growth in recognition of the importance of integrated working accompanied by a repositioning of service users from passive recipients to active partners in care and in the design and delivery of services (see Thorne et al., 2000; Branfield and Beresford, 2006; WAG, 2007), the fundamental inter-dependency of involvement, integration, partnership working and CCM has been highlighted, *inter alia*, by Holman and Lorig (2000) Longley (2013) Baggott (2013) and Coulter et al. (2013). Davies et al. (2009) emphasise that this is particularly relevant to the management of chronic conditions, considering that clients and informal carers frequently monitor, coordinate and implement their own treatment plans.

Indeed, the Health and Social Care Act (2001) set out statutory requirements for all decision-making of care to involve patients and carers, with Parsons et al. (2010, p. 4) noting that this includes, 'involvement in the design, planning and delivery of

health services'. Newman (2001) notes that such involvement was a fundamental principle of the Health Action Zones, where consumers and communities were integral to the implementation of new policy. Just as Health Action Zones were designed to provide a framework within which the NHS, local government and a wide range of stakeholders could combine to address health issues in socially deprived areas (Cole, 2004), so current UK-wide and Welsh policy emphasises that partnerships should involve a three-way system of joint agreement between health care providers, social care providers and clients (Carnwell and Carson, 2009). Indeed, the last decade has seen a number of Welsh Government documents incorporate a socially inclusive philosophy promoting local community involvement, citizen-centred services and client and carer participation (see, for instance, WAG, 2006a; 2007; 2007a). These are themes that also underpin the Welsh CCM Model: hence, it was indicated in *Designed to Improve Health and CCM in Wales* (WAG, 2007) that it would incorporate integration and partnership at all levels of care and that it would, moreover, promote client and carer empowerment and involvement.

These are themes to which I return in Chapter Seven, 'Integrated working and community engagement: rhetoric and reality', when I explore the extent to which people living with chronic conditions in the Bro-y-Grug locality were involved in the reconfiguration of services during the creation of the new CCM service. In the next section of this chapter, however, I briefly describe the Welsh Government's plans for implementing and testing the Welsh CCM Model and provide some background information about the case study locality of Bro-y-Grug.

The National CCM Demonstrator Programme and the case study locality

Having introduced the Welsh CCM Model in *Designed to Improve Health and CCM in Wales* (WAG, 2007), the Welsh Government subsequently detailed plans for its three-year implementation in *Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-2011* (WAG, 2008; henceforth *Service Improvement Plan*). Following the latter document's publication, the Welsh Government set up The National CCM Demonstrator Programme and launched three demonstrator-sites in three areas of Wales, with the aim being to:

Provide and test a sustainable, affordable generic CCM service model that supports people's needs locally and promotes independent living within the community in order to communicate and inform service change across Wales (WAG, 2009a, p. 5).

One of the three demonstrator-sites was located in the south Wales unitary authority of Armorshire. The Armorshire demonstrator-site, known as the Armorshire Chronic Conditions Collaboration (henceforth Armorshire Collaboration) was launched in May, 2008 and ran until March 2011 (NHS Wales/CCM Demonstrators, 2009). In *The Chronicle: Newsletter Issue 2* (NHS Wales/CCM Demonstrators, 2009f) it was explained that the Armorshire Collaboration was split into the three localities of Tregwen, Aberwrach and Bro-y-Grug. The main points of focus of this case study were the implementation of the Welsh CCM Model and the launch of the new CCM service in the locality of Bro-y-Grug.

Bro-y-Grug has a mix of urban and rural areas, numerous small towns and villages and a main market town of Llannuon. Although Bro-y-Grug's economy was traditionally driven by coal-mining, the industry's demise in the last quarter of the twentieth century has had a significant impact on a locality that had hitherto enjoyed relative prosperity. Moreover, a high proportion of people aged sixty-five and over who spent their working lives in the mining industry are now living with chronic obstructive pulmonary disease (COPD). This was one of the main reasons why, in 2006, Armorshire Local Heath Board (LHB) launched a new nurse-led Chronic Disease Management (CDM) Team. The latter was one of a number of small services that helped pave the way for Armorshire's involvement in the National CCM Demonstrator Programme. In Chapter Four, 'Setting the context for the case study', I describe in detail the resource base of services for people living with chronic conditions in Armorshire prior to the launch of the Armorshire Collaboration.

In addition to a high prevalence of COPD, however, Bro-y-Grug has experienced major demographic and epidemiological changes in recent years, with the locality's population of older people living with all chronic conditions, in turn, growing significantly. (As regards ethnicity, over ninety-nine percent of the residents of Bro-y-Grug are White). Whilst I revisit the selection of Bro-y-Grug as the case study site

in Chapter Three and provide more background information about the locality in Chapter Four, in the next section of this chapter I describe my interest in integration and the care of people living with chronic conditions.

Researcher background

Having worked for a number of years as an English and French teacher, in my mid-thirties – after considering the change for some years – I applied to train to become a nurse, and was accepted at Swansea University. Beginning my studies in March, 2006, over the course of the subsequent three years I regularly observed – during my placements in both community- and ward-based settings – what I perceived to be a frequent lack of joined-up working in the care of older people (many of whom were living with chronic conditions). The result of this was that, despite the high-quality care that was invariably provided by individual health and social care practitioners, older people often struggled to navigate their way through the complexities of convoluted systems and, as a result, often did not receive the care they required where and when they needed it. Moreover, I also noticed that whilst some people were admitted to hospital who could, I felt – and with adequate support – have remained living independently in their own homes, others were unable to return home following secondary-care treatment due to factors which, to my inexperienced eyes, had little to do with health and wellbeing and more to do with systemic failures.

My interest in this area only grew during the latter part of my nurse-training, a three-month 'management-placement' on an oncology and haematology ward of a local hospital, where I was brought into regular contact with the difficulties in organising long-term care for people whose needs regularly crossed the health and social care boundary. Indeed, having graduated, I was preparing to apply for a position as a staff nurse on this ward when my personal tutor advised me that interviews would soon be taking place for a PhD scholarship on the subject of integrated working in the care of people living with chronic conditions. Given my burgeoning interest in this field, I applied. Whilst I was surprised even to gain an interview, I was even more so to be offered the scholarship, but did not hesitate in accepting. Within a matter of weeks my research had begun and I was able to try and discover for myself

what lay behind the apparent difficulties of securing joined-up care that I had so far observed. As will, I hope, become evident in the course of this case study, the answer is far from straightforward. In the next section I set out the study's aim and objectives.

Aim and objectives

Thus far in this chapter, I have explained that changing illness patterns and growing numbers of older people living with chronic conditions are placing increasing pressures on health and social care systems worldwide, systems which were designed for acute and episodic illness rather than chronic long-term care. I have indicated that many countries – including Wales and the rest of the UK – have looked to integration in order to address these challenges. I have noted, however, that the evidence base for integrated working in health and social care is questionable, particularly in terms of its influence on the care of people using health and social care services and their involvement in the design and delivery of services. This is despite widespread agreement that the goal of integration is to improve care delivery to service users, and that it is their and their carers' perspectives that should determine the organisation of integrated care.

In this thesis, I sought to address these issues by exploring the establishment of a new integrated CCM service, using a qualitative case study approach (underpinned by an interpretevist stance) that incorporates multiple perspectives, including those of the people living with chronic conditions (and their carers) for whom the new service was created. My aim in conducting the case study was to answer the research question: How has integrated care for people living with chronic conditions developed during the implementation of the new CCM service? My objectives, in turn, were to answer the following five sub-questions:

1. How have different stakeholders been involved in the establishment of the new CCM service?
2. What do the stakeholders involved in the establishment of the new CCM service say about integration?

3. What do people living with chronic conditions and their carers say about the new CCM service and the care they receive?

4. What do front-line health and social care professionals say about their work in the new CCM service compared to their work in their previous teams?

5. How has the development of the new CCM service been affected by pre-existing services, roles and relationships and concurrent developments in health and social care?

I will address the five objectives, not individually and consecutively, but by incorporating them into a narrative account of the development of the new CCM service and, in so doing, will address the study aim. The narrative account will involve description and analysis of various aspects of the establishment of the new CCM service, including: the resource-base of CCM services and network of relationships that existed prior to the project's launch; contextual issues, such as rising numbers of older people living with chronic conditions, financial constraints and the introduction of a new strategy; the project's original organisational structure and its subsequent replacement; the way in which changes were communicated to front-line health and social care professionals and the latter's engagement in the service reconfiguration; information-sharing, communication and engagement with service users and carers; and the involvement of voluntary/third sector representatives. In the next section, the last of this introductory chapter, I provide an overview of the thesis.

Overview of the thesis

This thesis comprises seven further chapters. In Chapter Two, 'Integration and the management of chronic conditions: a review of the literature', I explore the terminological and definitional issues that have hampered the development of integration and integrated care. I discuss why it is widely considered that integration is key to improving the care of people living with complex needs and chronic conditions. I then examine evidence-based practice and implementation research, before turning my attention to the evidence base for integration and issues of assessment, including the difficulties in measuring integration, especially in terms of service user outcomes. Subsequently, I explore some of the key determinants of integrated working, before ending the chapter with an examination of patient and

34

public involvement initiatives.

In Chapter Three, 'Methodology and methods', I describe my use of a qualitative case study approach and my interpretevist stance and why I felt that these choices were appropriate to meeting the study's aim and objectives. I consider issues of access, ethical approval and sampling, including my selection of the creation of the CCM service in the Bro-y-Grug locality as the 'case' of this case study. I discuss the four methods of data-collection that I used, namely non-participant observation, individual semi-structured interviews, focus groups, and documentary research. I also discuss my handling and analysis of data and issues of rigour.

Chapter Four is entitled 'Setting the context for the case study'. In this chapter, I briefly situate the Armorshire Collaboration within its socio-economic and political context by way of an introduction to the environment into which the project was launched. I explore some of the underlying principles of the Welsh CCM Model and the National CCM Demonstrator Programme. I set Bro-y-Grug within the county-wide context, outlining some of the locality's salient socio-economic features whilst drawing attention to the contribution of existing services to the care of people living with chronic conditions in the years preceding the launch of the Armorshire Collaboration. I end the chapter with a brief examination of issues of timing that affected the project's development.

Chapter Five is entitled 'The prioritisation of service users: project leaders' vision of integration' and is the first of the case study's three findings and discussions chapters. After briefly revisiting the pre-existing resource-base of services, I examine how lead agency representatives involved in managing and leading the project (henceforth 'project leaders') argued that prevailing health and social care structures were obsolete, ill-suited to existing needs and that services were correspondingly fragmented and duplication- and gap-ridden. I explain that a number of project leaders – who could be considered local 'champions of change' – believed that the solution to these problems lay in increased integration and that their conceptualisation thereof was one of service user-centred care. I end the chapter by noting that extraneous factors meant that the team that led the Armorshire

Collaboration in the Bro-y-Grug locality was only established when the project was over half-way through its three-year duration.

Chapter Six is entitled, 'Flux, ambiguity and time-pressures: the impact on the Armorshire Collaboration'. Following on from Chapter Five, in this chapter I contrast the significant time-delays in establishing key components of the Armorshire Collaboration with the contention that the project had served as a catalyst for change. I examine how project leaders discussed the complexities of providing care for people living with chronic conditions, and the pressures of demographic changes and financial constraints. I describe how the belated entrance of a new strategy created ambiguity *vis-à-vis* the project's aims and contrast the advocacy of linguistic clarity and consistency with the widespread use of nebulous language and the terminological flux that surrounded the project. I explore the project's original organisational structure (and its subsequent replacement) and contrast the considerable contextual (and time-consuming) challenges that confronted project leaders with the Welsh Government's desire for rapid change. I end the chapter by describing how a project originally premised on a local approach to change appeared to have been instead organised hierarchically.

Chapter Seven is entitled, 'Integrated working and community engagement: rhetoric and reality'. In this chapter, I describe the Welsh Government's vision of partnership working premised on service user participation, involvement and empowerment and explain that similar values – together with the promotion of self-care and self-management – underpinned the Welsh CCM Model, the National CCM Demonstrator Programme and the Armorshire Collaboration. On the one hand, I describe how project leaders suggested that the Armorshire Collaboration would involve all stakeholders and that this would be built on effective communication in the development of integrated working. On the other hand, however, I explain that front-line professionals, service users, carers and voluntary/third sector representatives alike reported having little (or no) involvement in or knowledge of the reconfiguration of services in the Bro-y-Grug locality. I conclude the chapter by briefly discussing the extent to which the Armorshire Collaboration – in the Bro-y-Grug locality – provided an integrated approach.

In Chapter Eight, 'Discussion, final conclusions and implications', I discuss the extent to which the study's aim and objectives were met. I explore the strengths and limitations of the case study, before describing its original contribution to the evidence base of integrated working and chronic conditions management. Subsequently I review the main findings of the case study. I end the chapter by discussing the implications of my research in terms of the future development of health and social care integration and the care of people living with chronic conditions and provide some recommendations for future policy, practice, research and education.

Summary

In this introductory chapter, I discussed the terminology and characteristics of chronic conditions, outlined the growth in prevalence of chronic conditions amidst demographic change and explained how this has placed health and social care systems worldwide under pressure. I considered the importance of self-management, empowerment and involvement to chronic conditions care. I described how different countries have sought to address current pressures on health and social care systems by looking to disease management and, in particular, to integration. I described the Welsh CCM Model and its core features of self-management, integration and empowerment. I discussed the National CCM Demonstrator Project and the case study locality. I provided information about my own interest in integrated working and the care of people living with chronic conditions, before ending with an overview of the thesis. In the following chapter, I discuss the literature of integrated working as it relates to the management of care of people living with chronic conditions.

Chapter 2: Integration and the management of chronic conditions: a review of the literature

Introduction

Having described the development of global interest in integration in health and social care in relation to chronic conditions management in Chapter One, in this chapter I examine how these subjects have been investigated by writers and researchers to date. I begin by describing my literature search strategy before examining the language of integration and the implications of the lack of consensus as to what integration means. I describe the widespread agreement that integration is a potential answer to fragmented health and social care provision and then explore evidence-based practice and implementation research. I then turn my attention to the evidence base for integration and issues of assessment, including the difficulties in measuring integration, especially in terms of service user outcomes. Subsequently, I explore some of the key determinants of integrated working, including structural and cultural issues, before ending the chapter with an examination of patient and public involvement initiatives.

Literature search strategy

In an effort to be as inclusive as possible of the range of perspectives inherent in integrated working, I reviewed a wide variety of literature. In so doing I adopted a systematic approach, thereby aiming to generate an understanding of the research field and to add to conceptual and theoretical developments (Aveyard, 2007). I only considered works in the English language. Publications came from a variety of sources and can be broadly divided into two categories: original empirical research incorporating accepted research methods to collect new data; and non-empirical work such as discussion papers, governmental and NHS policy reports, newspaper and magazine articles, expert opinion articles and press releases.

In reviewing the literature, I set out to identify research related to community integrated health and social care teams and the provision of services to adults and older people with chronic conditions. My initial searches of the literature

concentrated on the identification of published work up to ten years old or older works of seminal importance. However, given that in the wake of New Labour's 1997 general election victory Wales and the rest of the UK experienced an increased interest in joint-working (Dowling et al., 2004; Coyle, 2007), I extended this to examine research and legislation from the late 1990s and early 2000s.

I employed a number of techniques in conducting the literature review. I made electronic searches of databases including CINAHL, PUBMED, the Cochrane Library, ASSIA and PsycInfo. I manually searched health and social care journals. I retrieved relevant policy documents and guidelines from UK and Welsh governmental websites and other organisations with an interest in health and/or social care, such as the National Institute for Health and Care Excellence (NICE), the Social Care Institute for Excellence (SCIE), the King's Fund and the Nuffield Trust. I checked bibliographies of relevant studies and followed up references using a 'snowball technique' (Ridley, 2008).

During my initial searches it became apparent that a wide variety of terms that are broadly analogous both to integration and to chronic conditions are frequently used interchangeably. As a reflection of this terminological diversity, my searches of the databases incorporated a wide variety of keywords and combinations of terms, including: *chronic condition, long-term condition, chronic illness, long-term illness, partnership working, integrated working, collaboration* and *joint-working.* In order to appraise critically the articles that were identified, I consulted the Critical Appraisal Skills Programme (2006) and Polit and Beck (2005). Moreover, as an indication of the breadth of interest in integration in health and social care and chronic conditions management, I found that numerous associated themes have been – and continue to be – investigated by writers and researchers. However, given the restrictions of student research, it is impossible for me to review every area. Instead – and in keeping – with my inductive approach and my developing knowledge as research progressed, I focussed my attention on the following themes: the language of integration; integration and service fragmentation; evidence-based practice and implementation research; the evidence base for integration; assessment issues; the determinants of integration, including issues of structure and culture; and patient and public involvement initiatives. I begin by discussing issues of language.

The language of integration

Curry and Ham (2010) point out that there are many competing definitions of integration and integrated care. However, Nolte and Pitchforth (2014) argue that a key challenge to the development of this field is the lack of common definitions of underlying concepts, with commentators – such as Challis et al. (1998) and MacAdam (2008) – arguing that despite repeated calls for more clarity, integration has been dogged by a fundamental lack of understanding or agreement of what it means in practice. With Armitage et al.'s (2009) systematic literature review of health systems integration identifying seventy terms and phrases related to integration, in addition to one hundred and seventy-five associated definitions and concepts, it is perhaps little surprise that integration has been described as an, 'academic quagmire of definitions and concept analyses' (Howarth and Haigh, 2007, p. 1), or as a, 'rhetorical invocation of a vague ideal' (Powell and Glendinning, 2002, p. 3). Integration has been defined by the Care Services Improvement Partnership (CSIP)/Integrated Care Network (ICN) (2008, p. 17) as:

> ...a single system of needs assessment, service commissioning and/or service provision. These arrangements are managed together by partners from health and social care, who nonetheless remain legally independent. They will also need to work alongside service users, carers and the Third Sector to ensure viable and appropriate models of service provision.

Or by Gröne and Garcia-Barbero (2001, p. 7) as:

> ...a concept bringing together inputs, delivery, management and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve the services in relation to access, quality, user and efficiency.

Or by Leatt (2002, p. ii) as:

> ...the creation of a modernized, cost-effective system characterized by closer working relationships between hospitals, long-term care facilities, primary health care, home care, public health, social welfare agencies, schools, police and others whose services have implications for the determinants of health.

The CSIP/ICN (2008) suggests that in its most complete form, integration refers to a single system of service planning and/or provision put in place and managed together by partners from health and social care who nevertheless remain legally independent. Ham (2008) considers that integration is a single system of needs assessment,

commissioning and/or service provision that aims to promote alignment and collaboration between the cure and care sectors. Leutz (1999; 2005) suggests that integration is the search to connect health care systems (acute, primary medical and skilled) with other human service systems such as long-term care, education, and vocational and housing systems.

Just as integration appears to be a diverse and fluid term, it has been argued that terminological discussions have long been a feature of many other aspects of joint-working in health and social care (Banks, 2002). So much so that at the beginning of the new millennium – an age of burgeoning interest in integration between the NHS and local government (Baggott, 2011) – the literature of partnership-working was described as 'definitional chaos' (Ling 2000, p. 82). Huxham (2000), for example, explains that partnership, collaboration, co-ordination and integration are used interchangeably but describe different activities ranging from simple information exchange between separate agencies to full integration of service delivery. The analogous use of subtly different terms such as multidisciplinary and interdisciplinary[13] is referred to by Payne (2000) by Ouwens et al. (2005) and by Leathard (2003). Leathard (2003), for instance, lists more than fifty ways used to describe learning and working together in health and social care, and – foreshadowing Howarth and Haigh (2007) – likens the situation to 'a terminological quagmire' (2003, p. 5).

In a similar vein, Lazenbatt (2002, p. 84) explains that collaborative relationships existing in community health and social care have been variously termed networks, partnerships, collaborations, alliances, coalitions, cooperatives, affiliations, multi-disciplinary teams, joint ventures, mergers, and clinical teams. The language of joint-working in chronic conditions management is, it seems, characterised by a similar breadth of terminology, with Nolte and McKee (2008) explaining that it is variously termed: integrated care; co-ordinated care; collaborative care; managed care; disease management; case management; patient-centred care; chronic (illness) care; continuity of care; trans-mural care; and seamless care. Commentators have

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[13] Multidisciplinary teams are made up of a group of individuals who work alongside each other to meet the needs of the patient. Their interventions are parallel but not necessarily made in close collaboration. Generic therapy teams within a district general hospital typically adopt this approach. Interdisciplinary teams take a more integrated approach. They work together towards a single set of agreed goals and often undertake joint sessions (for example, a specialist team working on a neuro-rehabilitation unit or a community neuro-rehabilitation team would typically adopt this approach) (see DH, 2005b).

also drawn a distinction between integration and integrated care. Shaw et al. (2011, p. 3), for instance, note that:

> ...integrated care is an organising principle for care delivery that aims to improve patient care and experience through improved coordination. Integration is the combined set of methods, processes and models that seeks to bring this about.

This relationship between processes (integration), on the one hand, and outcomes (integrated care) on the other, is further described by Kodner and Spreeuwenberg (2002, p. 3):

> Integration is a coherent set of methods and models 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 goal 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. The result of such multi-pronged efforts to promote integration for the benefit of these special patient groups is called 'integrated care'.

The Effective Interventions Unit (2002) reports that when efforts to improve integration are beneficial to the end users – specifically those people with complex needs – the result is integrated care. As with integration, however, it appears that there is little consensus as to the meaning of integrated care. Minkman (2012, p. 347), for instance, notes that, 'Integrated care appears in a variety of forms and there is no uniform and accepted definition; nor are there clear boundaries of the underlying concepts'. Berchtold and Peytremann-Bridevaux (2011, p. 2) suggest that integrated care is a, 'polymorphous concept viewed and understood very differently between national systems as well as between the various actors within the health systems'.

Walker et al. (2013) conducted a qualitative study of the perceptions of integrated care of people aged fifty and over living with one or more chronic condition(s) in San Francisco, California, including focus groups (n=7) with people living with chronic conditions (n=44). In each focus group, the researchers began by asking participants to write down their definitions of integrated care. During the subsequent discussions, participants were asked to describe: their health care experiences in multiple settings; their satisfaction with services; their views on how doctors and

other caregivers should share information and work together; and their views of co-ordinated and integrated care in different health care settings. Walker et al. (2013, p. 6) found that whilst participants did not understand the meaning of the term 'integrated care', they were 'relatively clear' on the concept. However, suggesting that the 'jargon-laden' (2013, p. 6) terms of integration and co-ordination are not 'patient-friendly', Walker et al. (2013) argue that they do little to help communication with people living with chronic conditions and the general public.

In an evaluation of the English Department of Health's Integrated Care Pilots (RAND Europe and Ernst and Young 2012), the researchers examined sixteen English integrated care initiatives. Although each initiative had a different focus, all involved complex areas, including structured care for dementia, end of life care, long-term conditions, falls in people aged over sixty, chronic obstructive pulmonary disease and cardiovascular disease. The researchers combined quantitative methods (Hospital Episode Statistics, surveys of patient/service user experience and staff) and qualitative methods ('structured free-form' questionnaires, non-participant observation and semi-structured face-to-face interviews with staff [n=213] and patients [n=82]). Across all of the sixteen sites it was found that staff described and interpreted integrated care in different ways. Recognising that integrated care is understood in different ways by different people, Goodwin et al. (2012, p. 3) nevertheless point out that:

> At its heart, it can be defined as an approach that seeks to improve the quality of care for individual patients, service users and carers by ensuring that services are well co-ordinated around their needs.

In a similar vein, the House of Commons Health Committee (2012, p. 12) reports that integration is, 'not an end in itself. Rather, it is an essential tool to improve outcomes for individuals and communities'. Likewise, the National Collaboration for Integrated Care and Support ([NCICS], 2013, p.13) notes that integrated care is, 'a means to an end', the end being, it is stressed, an improvement in the experiences and outcomes of individuals and their communities. Just as the NCICS (2013) adds that integrated care involves people being partners in their own care and support, so the Integrated Care Network ([ICN], 2009) suggests that it encompasses: client and carer outcomes based on their needs and expectations; person-centred services drawing on the needs, preferences and lifestyles of individuals to determine how care

43

is provided; self-directed support including provision of service users with systems of increased control over how service budgets are used to purchase care; and the involvement of both service users and carers in the design and evaluation of integrated care services.

Mur-Veeman et al. (2003, p.11) likewise point out that, 'The essence of integrated care is that individuals receive the care services they are in need of when and where they need them'. With this in mind, Shaw et al. (2011, p.3) argue that those involved with planning and providing services must impose the service user's perspective as the 'organising principle'. Nevertheless, in a report on the measurement of people's experiences of integrated care produced by a multi-organisational team from the King's Fund, National Voices, the Nuffield Trust, and the Picker Institute Europe, Graham et al. (2013) noted that not only is there no consistent definition (or indeed model) of integrated care, but that the vast majority of definitions have been produced by policy makers from an organisational perspective and fail to take account of the perspectives of service users.

Whilst Kodner and Spreeuwenberg (2002) point out that a clear understanding of integrated care has been hampered by the lack of common definitions, Goodwin et al. (2004) note that there is also a general absence of a sound paradigm through which to examine the process. However, Kodner (2009) warns that when agencies are initiating integrated projects, the absence of commonly held understandings increases the likelihood of subsequent disagreement and imperils the chances of long-term success. In a similar vein, in their literature review of collaborative working in health and social care, Williams and Sullivan (2007) found that if terminology was not clearly demarcated at the initial stages of joint-projects, problems frequently ensued, with differing interpretations of its nature and purpose adversely effecting the chances of successful collaboration.

The CSIP/ICN (2008) reports that those involved in integrated projects need to use a common language to promote shared understanding and to avoid confusion in terminology that will otherwise hold back progress. In a similar vein, in her report into the foundation of an integrated health and social care team in south-west England, Hickey (2008) described the fundamental importance of the establishment – from the outset – of a shared language of integration for team members from

different professional backgrounds. This included decisions regarding the consistent use of terminology (such as whether to use the term 'client', 'service user', 'customer' or 'patient') and the clarification of specialist terms and acronyms that could otherwise militate against effective communication (Hickey, 2008, p. 23).

O'Hara (2006) argues that communication must remain an ongoing priority in joint-working, since even long-standing partnerships can be dismantled following perceived breakdowns in communication. The issue of language clarity emerged during Williams and Sullivan's (2009; 2009a-f) case study of five Welsh collaborative health and social care projects. The projects comprised: a health conditions management programme for people claiming incapacity benefit; an integrated primary, intermediate and community care and nursing service for adults; an integrated disability service for children; a co-ordinated health and social care service for people living with chronic conditions; and a multi-agency service for people living with long-term conditions and for older people. For each site, the researchers examined documentary material (including reports), held preliminary discussions with site leads/co-ordinators and conducted interviews (of an unspecified number) with managers and (allied) health and social care practitioners.

Williams and Sullivan (2009f) noted that one of the issues that emerged from the interviews was the relative importance of seeking absolute clarity of purpose (and intent) from all parties at the outset of the project, as opposed to the negotiation of sufficient consensus to promote collective action. On the one hand, Williams and Sullivan (2009f) indicated that this raised the issue of the extent to which insufficient clarity at project initiation may provoke conflict and dissent at a later point when potential divergences regarding purposes and modus operandi may emerge. On the other hand, however, Williams and Sullivan (2009f) posited that insistence on clarity could generate paralysis if partners were unable to reconcile their different values, motivations and views and that a degree of ambiguity might therefore be advantageous.

McLaughlin (2004), similarly, suggests that it is the very ambiguity of the concept of partnership which has allowed it to become so popular, arguing that it can provide the space for differing interpretations and allow room for manoeuvre. In a critical

45

examination of the conceptual basis of service user consultation with people from the deaf community, McLaughlin et al. (2004) term the absence of such precise definitions – in this instance, as it relates to consultation – as, 'useful ambiguity' (2004, p. 154). In a similarly pragmatic vein, rather than argue the primacy of a particular definition, Glasby and Dickinson (2008) and Williams and Sullivan (2010) suggest that it is important that stakeholders' agree on a shared understanding of joined-up working – irrespective of the particular term they adopt – and that this should be clearly set out at project initiation.

The setting out of a shared vision (Hudson et al., 1999) clarity and realism of purpose (Hardy et al., 2000) and agreement on a unified approach to partnerships (DH, 1999) have all been identified as key ingredients of successful joint-working. The importance of the establishment of a common purpose was emphasised in a report detailing the Lambeth Living Well Collaborative, a partnership platform for commissioning mental health services aimed at improving care for people living with long-term mental illness (Langford, 2013). The platform, Langford (2013) explains, included GPs, mental health commissioners, carers, peer supports, service users, information managers, clinical directors and representatives from the local authority, primary and secondary NHS providers, housing support and voluntary/third sector organisations. Langford (2013) reports that one of the key aims of partners was to work together to establish a 'ground-up' shared-vision towards which all partners could aspire.

Although Williams and Sullivan (2007) note that some have viewed a preoccupation with the language of joint-working as unhelpful, the recognition of the importance of terminological clarity to the developing field of integration that existed in the early 2000s (Ambrose, 2001) is still considered to be fundamental to its further development and to the application of research findings (CSIP/ICN, 2008). Conversely, in a literature review of the barriers and facilitators of inter-professional team-working in primary and community care, Xyrichis and Lowton (2008) reported that confusion over terminology has hindered its applicability as a variable in studies and that this may account for the lack of consistency reported in healthcare literature on the levels of collaboration in clinical settings.

But without clarity, suggest Armistead and Pettigrew (2004), the insistence of policy-makers on the benefits of integrated working risks colouring the language of integration with negative connotations. They caution that the word 'partnership', for instance, could become a byword for long unproductive meetings and legislation that forces unwilling partners into joint-working. The language of partnership, the ICN (2007) warns, could therefore become synonymous with a lack of motivation in the face of overwhelming bureaucracy. Indeed, whilst Alaszewski et al. (2003a) suggest that nebulous terminology often suits the purposes of the authors of policy documents – who present it, they argue, as a self-evident concept and thereby justify the avoidance of lengthy analysis – they emphasise that this does not help people on the ground who are trying to develop integrated services, or researchers who are trying to evaluate them. El Ansari (2011) argues that such a lack of conceptual consensus creates four main problems: there is little understanding of exactly what a given study is investigating; there are difficulties in comparing studies; there are issues in implementing the findings from studies in real life situations; and there are difficulties in generalising findings from one study to other situations.

Finally, it is perhaps worth noting that Goodwin et al. (2008) report that definitional issues were considered important enough to constitute a major theme in Professor Kodner's closing remarks of the 8th Annual Integrated Care Conference in 2008. Goodwin et al. (2008) note that Professor Kodner used the forum to remind the audience of the importance of precise and unambiguous terminology, stressing that this was essential for the establishment of an intellectual and theoretical basis of integration in health and social care that would allow development of future policy and practice. Having discussed the language of integration, in the next section I discuss why integration is considered so important in health and social care.

Integration and service fragmentation

Notwithstanding Professor Kodner's warning of the need for greater linguistic clarity in the development of integration, he has also noted (Kodner, 2009a) that integrated strategies in health and social care are becoming increasingly popular worldwide. The reason for this, explains Glasby (2012), is that irrespective of the structure of local and national health and social care services, they often work with people with

complex, cross-cutting needs who require a coherent and joined-up response from a range of agencies. The multi-faceted nature of complex societal issues led to Rittel and Webber's (1973, p. 160) coining of the phrase 'wicked problems' (often referred to as 'wicked issues') as a reflection of the variety of factors that makes each individual case unique and inherently intractable. Williams and Sullivan (2009, p. 5) note that:

> The metaphor of a 'wicked issue' is often used in relation to health and social care because the challenges presented are complex and difficult to resolve and require action across a range of different boundaries including geographic, administrative, professional and sectoral. It is generally considered that the management of such challenges cannot be undertaken by single organisations acting autonomously; rather, they require people and organisations to collaborate in various ways through networks, partnerships and alliances.

According to the Audit Commission (AC) (1998), one of the five main reasons that agencies develop partnerships is to tackle such 'wicked issues', with Glasby (2012) noting that this requires policy makers to adopt various forms of multi-agency response. According to Sullivan and Skelcher (2002), such a response draws on a range of actors who each have complementary perspectives, expertise and resources, with Kooiman (2000, p. 142) noting that:

> No single actor, public or private, has the knowledge and information required to solve complex, dynamic, and diversified problems; no actor has an overview sufficient to make the needed instruments effective; no single actor has sufficient action potential to dominate unilaterally.

Many experts have indicated that integration is the most suitable way of providing care to an identifiable group of people who have complex needs (Henwood and Hudson, 2009; ICN, 2009; Goodwin et al., 2012). This can be contrasted with people whose health and social care needs are less complex, easier to manage, and therefore better served by more basic systems of care (Leutz, 1999; 2005). On the contrary, Leutz (1999; 2005) notes that it would be inefficient and economically unsustainable to use an integrated approach for everyone requiring care. Instead, Leutz (1999; 2005) notes, it is important to target funding for integrated care at those who have more complex and hence more expensive needs, such as people living with chronic conditions.

Busse et al. (2010) indicate that whilst people living with chronic conditions may require different medical interventions, they frequently require care from different providers from both health and social care. Safford et al. (2007) note that aside from medical issues, chronic conditions management comprises wider socioeconomic, cultural and environmental factors and must also take into account individual behaviour. Alongside the physical implications of living with specific chronic conditions, Field and Kelly (2003) point out that sociologists have stressed that living with a chronic condition has social and psychological implications. Field and Kelly (2003, p. 118) note, for example, that people living with chronic conditions must cope with: changes in relationships with family and friends; reorganising life expectations; adjusting to the limitations caused by the conditions; and dealing with economic disadvantage and various degrees of discrimination. Over sixty years ago, Parsons (1951) argued that illness should be viewed as a social phenomenon and understood in terms of social functioning. Goffman (1963) subsequently sought to understand people's experiences of living with chronic conditions and their day-to-day coping mechanisms. Bury (1982, p. 169) developed the concept of the 'biographical disruption' of chronic conditions and the way in which the unpredictable and intractable nature of rheumatoid arthritis, for instance, affects people's lives.

According to Taylor and Bury (2007), the meanings and significance of chronic illnesses to the individuals and groups whose identities are affected by them have been well documented. Amongst the themes discussed in relation to the sociology of living with chronic conditions are the loss of identity, disguising symptoms, social exclusion, stigma, the impact of illness on relationships and life chances and the narratives that people use to explain and make sense of chronic illness within the context of their biographies (see, for instance, Charmaz, 1983; Williams, 1984; Frank, 1995; Kelly and Field, 1996; Kelly and Millward 2004). Just as Hydén (1997) points out that these narratives lie outside the domain of the biomedical sphere, so it has been argued that caring for people with chronic conditions involves a complex interplay between medical, psychological and social problems (Strauss et al., 1984), must strike a balance between treatment regimens and overall quality of life (Larsen, 2013) and therefore requires a co-ordinated response from a range of providers from the cure and care services (WHO, 2002; Bigby, 2004). This means, it

is argued, that systems of care should take into account people's socio-cultural milieux in addition to holistic, physical, and emotional factors (WHO, 2008). Indeed, this awareness of the wider factors that impact on wellbeing should, it is argued, be central to partnership working between health and social care (Improvement and Development Agency [IDeA]/Audit Commission [AC], 2006; Woodard, 2007).

Twigg (1998) notes that the long-term nature of the care of people living with chronic conditions means that it falls across the boundary of medical and social care, with Kodner (2006) reporting that the integration of health and social services is called for in the care management of people living with chronic conditions since their needs are part healthcare and part social care and involve all aspects of day-to-day life. Kodner (2006) adds that in both community and institutional settings, people living with chronic conditions require a variety of services delivered by a range of health care and social care professionals. In a similar vein, Billings et al. (2013, p. 7) note that, since they cannot be 'cured', people living with long term conditions fall outside the traditional medical binary-code of 'well versus ill'. Accordingly, Billings et al. (2013, p. 7) indicate that they require, 'care, assistance, social support and rehabilitation to accomplish instrumental activities of daily life', functions for which health care organisations are, they suggest, 'poorly organised'.

Instead, it is argued that the care of people living with chronic conditions calls on the involvement of many different professions, from medical and nursing teams to social work, domiciliary care, physiotherapy, occupational therapy, dietetics and podiatry (Alabaster, 2006). Whilst Davies et al. (2009) likewise note that a broad range of skills is required to meet the challenges of promoting and maintaining optimum health status for people living with chronic conditions, Coulter et al. (2013) nevertheless contend that the need to improve the treatment and management of long-term conditions is the most significant challenge facing the NHS. Coulter et al. (2013, p. 2) argue that this, 'must involve a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive'.

In a similar vein, Goodwin et al. (2012) note that in view of the ageing population and increased prevalence of chronic diseases, it is necessary to move away from the current emphasis on acute care towards prevention, self-care, more consistent standards of primary care, and care that is well co-ordinated and integrated. Minkman et al. (2009), likewise, suggest that current care delivery for people living with chronic conditions is often fragmented and characterised by duplication, gaps in service and lack of continuity. In the words of the House of Commons Health Committee (2012, p. 7):

> The evidence is therefore clear: many older people and those with disabilities and long-term conditions need to access different health, social care, housing and other services, often simultaneously. Unfortunately the evidence is also clear that these services are fragmented, and those who need to rely on them often find that they are hard to access and that there are inadequate links between them.

The Welsh Government notes that the situation has been mirrored across Wales, with people living with chronic conditions and care providers consistently describing service provision as, 'fragmented, inconsistent, wasteful of time and resources, difficult to navigate and frustrating' (WAG, 2008, p. 11). The Welsh Government also draws attention to the existence of, 'research and anecdotal evidence that services are fragmented, both within and across organisational and sectoral boundaries' (WG, 2013a, p. 3). According to Rand Europe and Ernst and Young (2012, p.11), the improvement of outcomes for people living with chronic health problems by solving the issues of fragmentation is the, 'overarching aim of integrated care'.

However, the recognition of the need for a holistic approach to the multi-factorial problems of people living with complex needs has also coincided with a growing specialisation in health and social care professions, explain Jelphs and Dickinson (2008). This, it is argued, has added to the fragmentation of health and care services, with each specialisation provided by different organisations, including governmental and non-governmental bodies, community groups and private enterprises (Andersson et al., 2011). But with Douglas (2009) noting that the more complex the problem, the greater the need to work together, Axellson and Axellson (2006) warn that a

growing differentiation of providers has seen a growing need to integrate to avoid fragmentation of services.

According to many commentators (for example, Nies, 2004; Mur-Veeman et al., 2008; Kodner, 2009; Curry and Ham, 2010) a host of countries face similar pressures to adapt their fractured health and social care systems to the shift in the global burden of disease from acute illness to chronic conditions. This situation reflects the fact that the traditional focus of health-care systems worldwide has been on acute and episodic models of care, with providers unaccustomed to working collaboratively (Nolte and McKee, 2008). Indeed, whilst contextually-specific issues relating to chronic conditions affect how different countries approach care management, they share broad similarities of care provision, given that most healthcare systems worldwide developed in order to respond to acute episodic illness (Glasby, 2012). In such systems, the people that require long-term care services are poorly served and faced with services that are missing, function in isolation or are poorly co-ordinated (Demers and Lavoie, 2008).

Indeed, a quarter of a century ago, Strauss and Corbin (1988) predicted that major health care changes would be necessary to cope with growing numbers of older people and frequency of chronic conditions. In order to co-ordinate effectively the different elements of care and to address the lack of joined-up working, many countries are therefore employing integrated approaches to the organisation of chronic conditions management (Antunes and Moreira, 2011). Goodwin et al. (2012) likewise note that most western developed nations are trying to shift the balance of care away from acute care by means of integration. Prior to examining the extent to which this approach is supported by existing evidence from research (see section, 'The evidence base for integration' below), in the next section I consider evidence-based practice and implementation research.

Evidence-based practice and implementation research

Following the UK general election victory of 1997, New Labour proposed a more pragmatic and evidence-driven approach to policy and guidelines in health care, as outlined in the Command Paper *The New NHS: Modern Dependable* (DH, 1997).

Not only was it stressed in the document that the NHS would be based on partnership working, but that the provision of health and social care would be built on evidence-based practice. With evidence-based practice central to a series of UK and Welsh policy documents published soon after the 1997 election victory, in addition to *The New NHS: Modern and Dependable* (DH, 1997) its importance was set out in, for instance, *Putting Patients First* (Welsh Office, 1998) and *Clinical Governance: Quality Care and Clinical Excellence* (Welsh Office, 1999). Moreover, these documents would be followed by the inauguration of NICE to develop evidence-based guidance around clinical- and cost-effectiveness (Glasby, 2012) and the launch of National Service Frameworks (NSFs), which set evidence-based national standards and service models for a defined service or care group (Chapman and Adam, 2001).

According to Long and Harrison (1996), evidence-based practice describes the use of contemporaneous research findings as the basis for clinical decision-making. Parahoo (2006) adds that evidence-based practice combines available evidence with clinical expertise and patients' wishes, with Melnyk and Fineout-Overholt (2005; 2005a) explaining that this enables clinicians to provide the highest quality care to meet the complex needs of patients and their families. Davies (2004, p. 3) notes that evidence-based practice, 'helps people make well-informed decisions about policies, programmes and projects by putting the best available evidence from research at the heart of policy development and implementation'.

A number of commentators have referred to a growing awareness of the importance of evidence-based practice in informing the development of practice and policy-making in health and social care and of growing pressure on policy-makers to ensure that policy is evidence-based (see, for instance, Murray and Lopez, 1996; Hanney et al., 2003; Muir Gray 2004; 2009; Ward et al., 2006; Nutley et al., 2007; Rycroft-Malone, 2008; Lavis et al., 2009). However, it has been argued that although research evidence itself has grown substantially, a concomitant translation into practice has not been forthcoming (Fixsen et al., 2005; Ward et al., 2006; Rycroft-Malone, 2008; Aarons et al., 2011; Nelson, 2011). On the contrary, a discrepancy between the numbers of people who could potentially benefit from evidence-based interventions and those who actually do so has been widely noted (see, for instance,

53

McGlynn et al., 2003; Glasgow et al., 2004; Nutley et al., 2007; Glasgow, 2008; Abildso et al., 2010).

Burke et al. (2012, p. 2) explain that the disparity between advances in knowledge and outcomes is commonly termed the, 'implementation gap' (analogous terms such as 'implementation failure' and 'implementation deficit' are also used [see Hill and Hupe, 2002]) and that this equates to the, 'difference between the evidence of what works in theory and what is delivered in practice'. The pervasiveness of the implementation gap in the field of health and social care has been widely acknowledged, with frequent reports that programmes designed to improve the quality of services and outcomes for service users have failed to reach their full potential due to issues related to implementation (Eccles et al., 2009; Aarons et al., 2010; Grimshaw et al., 2012; Colquhoun et al., 2014).

However, Guldbrandsson (2008) explains that, in order to achieve a successful outcome, not only the new intervention but also the process of implementation must be well-functioning, so that just as a poor intervention will have little effect if well implemented, a good intervention will have little effect if poorly implemented. Accordingly, a precondition of evaluating the success of the implementation of a new intervention is the ability to distinguish between the intervention and the process – or strategy – of implementation (see, for instance, Greenhalgh et al., 2004; Fixsen et al., 2005; Peters et al., 2013; 2103a). This distinction is illustrated by Peters et al. (2013), who explain that whilst the provision of a vaccine is an example of a health intervention, the outreach clinics and supervision checklists used to improve the coverage and quality of immunisation are examples of strategies of implementation.

Though the complexities of implementation mean that definitions of it are many and varied (see, for instance, Hill and Hupe, 2002; Gulbrandsson, 2008; Hill, 2009) in the context of evidence-based practice, it has been termed a, 'specified set of activities designed to put into practice an activity or program of known dimensions' (Fixsen et al., 2005, p. 5). But just as Peters et al. (2013) draw attention to the importance of distinguishing between an intervention and an implementation

strategy, so they note that it is important to distinguish between 'implementation' and 'implementation research'. The latter, explain Peters et al. (2013a, p. 1), is:

> ...the scientific inquiry into questions concerning implementation – the act of carrying an intention into effect, which in health research can be policies, programmes, or individual practices (collectively called interventions).

A growing interest in such inquiry in the context of health and social care has seen the development of a plethora of competing terms. Inevitably, I use some of these terms in this section. For the most part, however, I refer to implementation research. The reasons for this are twofold: firstly, because Eccles et al. (2009, p. 2) note that in the UK, the latter term seems to be the, 'best recognised'; secondly, because implementation research also appears to be the favoured term of *Implementation Science*, considered the, 'leading international journal' of research into the implementation of evidence-based practice (Glasgow et al., 2012, p. 1275). Whilst the journal's introductory web-page *About Implementation Science* (Implementation Science, 2015) provides a definition of implementation research, it does not do so for, 'implementation science' (this despite the journal's name and the web-site's title). Elsewhere, however, the latter has been termed the, 'study of how evidence-based or evidence-informed practices and innovations are adopted, replicated, and scaled up in diverse practice settings' (Person et al., 2014, p. 8).

Peters et al. (2013a) note that implementation research considers the factors affecting implementation, the processes of implementation, and the results of implementation, including the introduction of potential solutions into health systems and the promotion of their large scale (sustainable) use. Peters et al. (2013a) point out that of central importance in implementation research is context, including social, cultural, economic, political, legal and physical environments, institutional settings, stakeholders (and their interactions) and demographic and epidemiological conditions, with particular interest paid to the structures of health systems and the role of governments, non-governmental organisations, providers and citizens. Schillinger (2010) indicates that implementation research has the following goals: the generation of new insights and generalisable knowledge *vis-à-vis* the processes

of dissemination[14]and implementation and related facilitators, barriers and strategies; the application and testing and refinement of models, theories, hypotheses, and principles; and the production of reliable strategies for improving health-related processes and outcomes for both local and other settings and groups.

Peters et al. (2013) point out that implementation research plays an essential role in ensuring the realisation of the benefits that accrue from the effective implementation of policies, programmes and services and the concomitant development of knowledge. In the absence of implementation research, argue Peters et al. (2013, p. 61), valuable resources are committed to new innovations in the 'naïve hope that things will work out'. This is an approach which can prove extremely costly, warn Peters et al. (2013), since programmes that fail because their designers had paid insufficient attention to context-specific factors can result in wasted resources and unnecessary human suffering. But despite its importance, stress Peters et al. (2013, p. 61), implementation research is a 'neglected field of study'.

With Eccles et al. (2009, p. 3) noting that this neglect extends to the UK, they explain that implementation research is not a recognised area of funding in the NHS and, as a consequence, 'lacks profile'; this is a situation that Eccles et al. (2009, p. 3) attribute – to some extent at least – to the fact that implementation research is a 'relatively young science'. But if implementation research is a young and emerging field of study in the context of evidence-based practice (see also Fixsen et al., 2005; Titler, 2008; Schillinger, 2010) in the context of public policy – where it is also frequently termed implementation research – it has a well-established heritage (see, for instance, Elmore, 1979/80; Hill and Hupe, 2002). O'Toole (2000, p. 266) explains that in the public policy context, implementation research, 'concerns the development of systematic knowledge regarding what emerges, or is induced, as actors deal with a policy problem'.

Given its long tradition, developments in implementation research in the field of public policy have influenced the more recent implementation research in the field of

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[14] Dissemination, according to Schillinger (2010, p. 1), is, 'the targeted distribution of information and intervention materials to a specific public health or clinical practice audience'.

evidence-based practice (see, for instance, Bergen and While, 2005; Fixsen et al., 2005). Indeed, with Peters et al. (2013, p. 27) noting that a 'great strength' of implementation research in health and social services is its capacity to draw on multiple perspectives and multi-sectorial insights and to 'tap into different sources', Burke et al. (2012) argue that it is important to recognise the important insights – when researching the implementation of health and social care initiatives – that can be gained by examining the implementation of public policy.

The latter, notes Hill (2009), became the focus of intense interest in the 1970s – in the wake of Pressman and Wildavsky's (1973) seminal work on the shortfall between government policy and its execution at local level – with a series of studies in the U.S. and Europe. Hill (2009) explains that subsequent developments would see the emergence of debates between proponents of 'top-down' and 'bottom-up' approaches to implementation. Advocates of the top-down approach, explain Howlett et al. (2009), see a clear distinction between policy formation and policy implementation, viewing effectiveness in terms of adherence to original policy intent. From this perspective, explains Hill (2009), if there are clear and robust causal links between goals and actions and appropriate resources and distinct chains of command, failure to implement policy can be attributed to errors in strategy and machinery. This approach, however, has attracted a number of criticisms, including: a neglect of the contribution of the actors at various stages of implementation beyond central decision makers; an incompatibility with complex situations involving multiple policies and agencies; an over-estimation of the impact of government action; and a reliance on unrealistic preconditions (Buse et al., 2005).

The bottom-up approach, on the other hand, sees the focus of interest shift to the influence of local actors affected by and co-responsible for implementation (Sabatier, 1986). Rather than drawing a rigid distinction between policy and implementation, there is acknowledgement of the interaction between agencies and individuals in shaping policy (Howlett et al., 2009). There is recognition, moreover, that even when conditions for implementation are optimal, change can still occur in unforeseen ways (Buse et al., 2005). Instead of judging the effectiveness of a programme in terms of adherence to central directives, the bottom-up approach

therefore places greater importance on how it is re-shaped on the ground in order to achieve given objectives (Howlett et al., 2009).

A notable influence in the study of policy implementation from the bottom-up perspective has been the work of Lipsky (1980) and his examination of the adaptive behaviour of those at the front-line of service delivery, whom he terms 'street level bureaucrats'. This has been of particular relevance to health and social care, inasmuch as it has been argued that front-line professionals in these fields possess much of the intellectual, creative and social care capital in healthcare organisations (Walshe and Smith, 2006) and are active in an environment where negotiation and conflict are inevitable (Buse et al., 2005).

Later theorists have sought to synthesise top-down and bottom-up positions in a manner which can reconcile the roles of professionals, service users and other stakeholders in the implementation of policy with the authority of central policy-making bodies (Hill, 2009). Barrett and Fudge (1981), for instance, have incorporated differential power and the involvement of higher level actors in negotiations as policies are applied. Elmore (1978; 1979/80) has suggested that in the study of complex events, mixed research methods in combination with a variety of theoretical models can produce a multi-level analysis and that 'forward mapping' and 'backward mapping' approaches can help policy makers identify the incentives that affect the behaviour of implementers.

In addition, Sabatier (1986) has proposed an 'advocacy coalition' approach to examine the implementation role of actors at different levels, whilst 'third generation' implementation theory has seen attempts to move beyond a perceived reliance on descriptive and fragmented analyses of earlier writers to develop explanatory and predictive implementation studies (see Goggin et al., 1990). According to O'Toole (2000), implementation studies have reached a point where the general strengths of bottom-up and top-down approaches have been recognised, with complementary research now commonplace. Indeed, according to Peck and 6 (2006) elements of both top-down instruction (emphasising adoption) and bottom-up negotiation (emphasising adaptation) should be part of any effective approach to implementation.

With Fixsen et al. (2005) noting that such wider developments have influenced current understanding of the development and evaluation of implementation as it relates to evidence-based programmes and interventions, they explain that their review of the literature of implementation research produced a commonality of factors and processes across many different domains. One such commonality, Fixsen et al. (2005, p. vi) emphasise, is that the use of systematic implementation practices, 'are essential to any national attempt to use the products of science – such as evidence-based programs – to improve the lives of its citizens'.

Attempts to ensure a systematic approach to the implementation of evidence-based practice in the UK saw the 2006 creation – at the request of the then Chief Medical Officer of England/UK Government Chief Medical Advisor Sir Liam Donaldson – of a High Level Group on Clinical Effectiveness[15] (Eccles et al., 2009). The request was made following Sir Liam Donaldson's report of the departure of clinical decisions from research evidence within the NHS and of unnecessary, 'clinical practice variation' (DH, 2005a, p. 16). The group – convened by Professor Martin Eccles at the request of chair Professor Sir John Tooke – was subsequently named the Clinical Effectiveness Research Agenda Group (CERAG: see Eccles et al., 2009). That it was considered necessary to convene such a group would seem to reflect the recognition of the necessity of employing a systematic approach to implementation and the acknowledgement that implementation is a challenging and complex process (see, for instance, Greenhalgh et al., 2004; Dopson and Fitzgerald, 2005; Australian Government/Australian National Audit Office, 2006; Institute of Medicine, 2007; Bond et al., 2009).

Indeed, the literature of the implementation of evidence-based practice frequently includes lists of potential barriers to this process. Barriers that have been identified include: an absence of personal contact between researchers, policy makers and practitioners; a lack of time, resources and encouragement; obstructive organisational structures and decision-making processes; inopportune timing of research; poor quality or limited availability of research; poor reporting of research;

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[15] Clinical effectiveness, according to the Royal College of Nursing (1996, p. 3), 'provides a framework for linking research, implementation and evaluation in clinical practice' and is concerned with, 'doing the right thing in the right way for the right patient at the right time'.

lack of authority for clinicians to make changes; negative attitudes about knowledge and use of evidence-based practice; political influence; professional and cultural factors; resistance to change; and vested interests (see, for instance, Elliott and Popay, 2000; Innvær et al., 2002; Petticrew et al., 2004; Cooksey, 2006; Mitton et al., 2007; Nutley et al., 2007; Armstrong et al., 2008; Bowen et al., 2009; Houser, 2011; Burke et al., 2012).

Alongside the barriers to the effective implementation of evidence-based practice, the literature contains numerous examinations of the factors that can facilitate this process. For instance, researchers have identified: global-level facilitators, such as the creation of international collaborations and associations and the use of scientific journals to circulate high quality research (Oliveri et al., 2004; Poolman et al., 2007); national-level facilitators, including governmental requirements to introduce the study of evidence-based practice in healthcare educational establishments or the creation and financing of regulatory professional bodies to assure quality and the use of guidelines (Al-Almaie and Al-Baghli, 2004; Melnyk et al., 2004; Ubbink et al., 2011).

Researchers have identified hospital board-level facilitators, such as the creation of research councils and the allocation of budgets to promote high-quality research (Mehrdad et al., 2008; Brown et al., 2009; Ubbink et al., 2011); management-level facilitators, including the evaluation of ward-level evidence-based practice activities, the building of an infrastructure and environment that support the use of evidence-based practice and the provision of non-patient hours for staff (Palfreyman et al., 2003; Gale and Schaffer, 2009; Brown et al., 2010; Ubbink et al., 2011); and educator-level facilitators, such as the formulation of curricula and educational programmes in collaboration with healthcare professionals and the use of interactive face-to-face education (Al-Almaie and Al-Baghli, 2004; Al-Omari and Al-Asmary, 2006; Poolman et al., 2007; Gerrish et al., 2008; Gale and Schaffer, 2009).

Researchers have also identified faculty and researcher-level facilitators, including the documentation, analysis and interpretation of the effectiveness of actions and the support of professionals in clinical settings (Mehrdad et al., 2008; Brown et al., 2009); service-level facilitators, including the provision of medical library facilities

60

and computer and internet facilities (Al-Almaie and Al-Baghli, 2004; Melnyk et al., 2004; Ubbink et al., 2011); workplace-level facilitators, including the provision of access to evidence-based practice mentors and time and personnel dedicated to evidence-based practice activities and regular research meetings (Andersson et al., 2007; Poolman et al., 2007). Finally, researchers have identified cultural-level facilitators, such as regular emphasis on the importance of evidence-based practice to daily practice and patient-care, the empowerment of nurses to influence change and the demonstration of willingness to facilitate the process of implementation (Parahoo and McCaughan, 2001; Amin et al., 2007; Gerrish et al., 2008; Brown et al., 2009).

There is some agreement, furthermore, that implementation is more effective when a variety of strategies is utilised (Fine et al., 2003; Schechtman et al., 2003; Gotham, 2004; Rohrbach et al., 2006). Guldbrandsson (2008), for instance, explains that the chances of successful implementation are enhanced by combining the distribution of guidelines for new routines with education, practical training, coaching, feedback and consultation. There is also some consensus that implementation strategies need to address the perspective of both the individual practitioner and that of the organisation (Katz et al., 2004; Greenhalgh et al., 2004; Murtaugh et al., 2005; Nieva et al., 2005). Jones et al. (2004) note that when, conversely, practitioners decide individually what evidence to use in practice, considerable variation in practice patterns results; such variation, warns Titler (2008), can lead to adverse patient outcomes.

A number of experts also note that implementation is not an event but a process that occurs in discernible and incremental stages (see, for instance, Fixsen et al., 2005; Guldbrandsson, 2008; Walshe, 2009; Saldana, 2014). Whilst Burke et al. (2012, pp. 6 – 8) indicate that the latter's exact number – and the labels and meanings assigned to them – may vary, they add that it is possible, in broad terms, to discern the four consecutive stages of 'exploring and preparing', 'planning and resourcing', 'implementing and operationalising' and 'business as usual'. It is also argued that in order to facilitate successful implementation, research evidence needs to be conceptualised, conducted and communicated in a manner that is meaningful to decision-makers (Davies and Nutley, 2002; 2008; Petticrew et al., 2004); that it needs to be accessed, assessed and properly applied (Bowen et al., 2009); and that

researchers and decision-makers need to work in partnership to fund and conduct research that addresses key policy questions (Nutley et al., 2007).

Another important factor that can facilitate the implementation of evidence-based practice, suggest Rycroft-Malone and Burton (2010), is the application of theoretical models or frameworks to the development and evaluation of interventions. Rycroft-Malone and Burton (2010) argue that this can help to identify appropriate outcomes, measures and variables – thereby paving the way for the development of further theory and focused and appropriate evaluation – as well as enhancing the understanding of what influences and mediates success. According to May (2013) the goal of the development of implementation theory is the production of a robust set of conceptual tools that can enable researchers and practitioners to identify, describe and explain important elements of implementation processes and their outcomes.

Rycroft-Malone and Bucknall (2010) explain, however, that there is no single theoretical model that represents all of the complexities of the implementation of evidence-based practice. On the contrary, Titler (2008) draws attention to the existence of multiple models that are used across a variety of clinical settings. But Titler (2008) adds that these models often include a number of common elements, such as: the selection of a practice topic (such as discharge instructions for individuals with heart failure); the critiquing and synthesis of evidence; the implementation and evaluation of the impact on patient care and provider performance; and the consideration of the context/setting in which the practice is implemented.

Peters et al. (2013) explain that many theoretical models of implementation of evidence-based practice attempt to explain individual or group behaviours around implementation issues. Peters et al. (2013) draw attention, for instance, to: the RE-AIM (reach, efficacy, adoption, implementation, and maintenance) framework, commonly used in health promotion interventions where it is used to provide a practical approach to evaluating the effects of health interventions through changes in individuals, organisations and communities; the Diffusion of Innovations Theory, which seeks to explain how innovations spread; and the Consolidated Framework for

Implementation Research (CFIR), developed as a way of consolidating the various theories and terms used to support further development of theory and testing *vis-à-vis* the translation into practice of effective health interventions.

In a review of 'knowledge translation' – defined by Grimshaw et al. (2012, p. 2) as the process of, 'ensuring that stakeholders are aware of and use research evidence to inform their health and healthcare decisionmaking' – Estabrooks et al. (2006) also draw attention to the existence of numerous models of research utilisation. In the field of the implementation of evidence-based practice in nursing, for instance, Estabrooks et al. (2006) list: the Conduct and Utilization of Research in Nursing (CURN) model, based on a problem-solving approach that sees knowledge transferred through linkages when a practice problem is encountered and which relies on a reciprocal relationship between the users and producers of knowledge; the Western Interstate Commission on Higher Education in Nursing (WICHEN) model, again based on a problem-solving approach, and which draws on concepts of diffusion of innovation and planned change and relies on nurses acting as organisational change agents; and the Iowa Model of Research Use in Practice, which sees triggers in practice acting as catalysts for knowledge-seeking and relies on clinicians incorporating research into practice when a trigger is encountered (and when traditional knowledge cannot be used to solve a problem).

However, just as Estabrooks et al. (2006, p. 25) report that there is, 'no satisfactory overarching knowledge-translation theory', they also note that the study of research into the implementation of evidence-based practice lacks terminological and definitional clarity. Indeed, in McKibbon et al.'s (2010) literature review of the language of knowledge translation, the researchers draw attention to the use of approximately one hundred terms – and lack of standardised definitions – to refer to related research; this is a situation which, the researchers suggest, is tantamount to a modern-day 'Tower of Babel' (2010, p. 1). Similar findings were recorded by Tetroe et al. (2008) in their study of knowledge translation in thirty-three research-funding agencies across Australia, Canada, France, the Netherlands, Denmark, Norway, Sweden, the UK and the U.S. Using semi-structured interviews with agency key informants and web-site information, Tetroe et al. (2008) identified twenty-nine definitions of knowledge translation to refer to various aspects of clinically effective practice. Noting that the lack of terminological and conceptual

clarity and consistency militated against an understanding of how and by whom knowledge translation should be operationalised, Tetroe et al. (2008, p. 152) stress that these factors constitute the 'largest looming barrier' to advancing the knowledge translation agenda.

But alongside McKibbon et al.'s (2010) reference to knowledge translation's 'Tower of Babel', Peters et al. (2013a, p. 1) draw attention to the 'confusion' surrounding the 'terminology and scope' of implementation research, just as Eccles et al. (2009, p. 2) note the analogous 'confusion' surrounding the terminology of clinically effective practice. Indeed, with the burgeoning interest in research into the implementation of evidence-based practice having witnessed the emergence of a host of related terms – such as 'quality improvement', 'dissemination', 'uptake', 'knowledge transfer', 'delivery science', 'research use', 'translational research', 'dissemination research', 'diffusion research' and 'knowledge translation' – there is widespread recognition that the field lacks terminological, definitional and conceptual cohesion (see, for instance, CERAG, n.d.; Fixsen et al., 2005; Tetroe et al., 2008; Damschroder et al., 2009; Eccles et al., 2009; Woolf, 2008; McKibbon et al., 2010; Schillinger, 2010; Makic and Fink, 2011; Glasgow et al., 2012; Colquhoun et al., 2014).

Fixsen et al. (2005) argue, however, that this lack of cohesion reflects the field's relative novelty. Indeed, it is this very novelty that, suggest McKibbon et al. (2010, p. 8), may account for the terminological flexibility of knowledge translation. But McKibbon et al. (2010) hasten to add that in order to facilitate the assessment of the application of evidence to practice, the creation of a standardised vocabulary for writing, collaborating, communicating and retrieving information is essential. In the continued absence of such a standardised vocabulary, however, it is argued that the plethora of terms – and concomitant variety of conceptualisations – continues to present a significant challenge to the effective promotion and support of the use of evidence in health and healthcare policy and practice (Lokker et al., 2015).

Indeed, acknowledging that implementation research is beset with 'taxonomic challenges', 'confusion regarding nomenclature' as well as 'significant debate' as to scope, Peters et al. (2013, p. 27) argue that the concomitant lack of understanding as to what implementation research is and the key role it plays in maximising the

benefit accrued from new interventions are amongst the principal reasons why it continues to be a neglected field of study that is beset – in the UK at least – by inadequate funding. But Peters et al. (2013) point out that it is possible to argue that, with many of the interventions and technologies that can reduce morbidity and mortality already in place, greater attention should now be paid to developing the implementation research agenda.

According to Peters et al. (2013), this development requires the following seven actions: recognition of implementation research as a core part of programme implementation; encouragement of researchers to become more engaged in programme activities; facilitation of increased accessibility to/participation in new programmes for researchers; increased funding for implementation research; increased training opportunities for implementation research; increased guidance and opportunities for mentorship to researchers and implementers; and incentives for researchers to become more engaged in making changes in policies and programmes and in academic publication and teaching.

It remains to be seen, however, what notice will be taken of those who call for greater interest in implementation research and the extent to which their arguments will lead to greater funding in this reportedly neglected field. Having explored evidence-based practice and implementation research, in the next section I consider the evidence base for integration.

The evidence base for integration

UK governmental support for the integration of services for the care of specific sub-sections of the population was set out as long ago as 1998 in the discussion document *Partnership in Action* (DH, 1998). In the document, the value of integration for the care of society's vulnerable groups was indicated, with the suggestion that this was an appropriate approach to meet the complex and changing nature of the needs of frail older people, adults or children with mental health problems and/or learning or physical disabilities. Similarly to Kodner (2006), it was noted that because these specific groups of people required input from a number of different agencies, optimum service delivery was achieved through integration of

services. Like the ICN (2004) and Leutz (1999; 2005) it was indicated that single agency working was inappropriate for the care of vulnerable people with complex needs. These people, it was noted, had suffered from an historic lack of co-ordination and fragmentation in service provision, caused by 'sterile arguments about boundaries' that left the most vulnerable in the, 'no man's land between health and social services' (DH,1998, p. 3).

The response was a period of heavy investment in local partnerships in the UK, with moderate estimates of total annual spending of £15 – 20 billion from the early 2000s (Sullivan and Skelcher, 2002). These partnerships, Sullivan and Skelcher (2002) explain, involved 75,000 people in 5,500 local projects relating to economic regeneration, rural transport, child development and health and social care. Contemporary commentators such as Miller and Ahmad (2000) underlined the extent to which partnership working was embedded in policy at this time. Moreover, not only did a series of government documents provide guidelines, but Section 31 Flexibilities of the Health Act (1999) were introduced to facilitate joint-working between health and social services and the NHS. Glendinning (2003) explains that this new legislation was not centrally defined and prescriptive but instead facilitated adaptation to local circumstances through a number of flexibilities, thereby allowing for: the pooling of health and social care budgets for specific services; the delegation of responsibilities and service planning and commissioning to one lead organisation working on behalf of all the partners; and the integration of health and social services within a single organisational, managerial and employment framework.

Just as the years following New Labour's 1997 UK general election victory were characterised by an increased interest in evidence-based practice, they also saw an increased emphasis on partnerships (see, for example, DH, 1997; 1998; 1999). In a similar vein, joint-working ran through a number of key policy documents in Wales (see, for, instance, Welsh Office, 1998; 1998a; NHS Wales/National Assembly for Wales [NAW], 2001; WAG, 2003). A similar insistence on the importance of integration also characterises more recent Welsh strategies relating to: the care of older people (WAG, 2007a; 2008c); to people living with chronic conditions (WAG, 2007; 2008); to people living in rural communities (WAG, 2009c); to primary and

community services (WAG, 2010); to health and social care staff (WG, 2012a); to older people (WG, 2013); and to older people with complex needs (WG, 2013a).

However, many commentators have argued that categorical proof of the effectiveness of integrated working is weakly supported by empirical research (El Ansari et al., 2001; Dowling et al., 2004; Glasby and Dickinson, 2008; Nolte and McKee, 2008; Carnwell and Carson, 2009; Dickinson, 2009; Perkins et al., 2009; Graham et al., 2013; Skills for Care, 2013). Evidence that supports the use of a variety of collaborative designs relating specifically to the care of people living with chronic conditions is also inconclusive (Ouwens et al., 2005). Perhaps most problematic of all have been reports of a dearth of evidence that integrated working benefits service users (El Ansari et al., 2001; Brown et al., 2003; Cameron and Lart, 2003; Glendinning, 2003; Kharicha et al., 2004; Townsley et al., 2004; Dowling et al., 2004; Davey et al., 2005; Dickinson, 2009; Shaw et al., 2011; Cameron et al., 2012). Armitage et al.'s (2009) systematic literature review of health systems integration, for example, draws attention to the dearth of empirical evidence of the impact of integration on outcomes; Powell and Dowling (2006) consider proof of effectiveness to be uncertain; and Williams and Sullivan (2007) note that there is little to show that partnerships have produced any changes (positive or negative) in health status or service provision.

In a literature review of research into the impact of partnership-working in the UK, Dowling et al. (2004) assessed the evidence concerning its effects and investigated the conceptualisation of 'success' in this field. The researchers identified thirty-six peer-reviewed research papers published after 1997 which made an explicit link between partnership working and success. On the one hand, the researchers noted that thirty-one papers focused on factors of process, examining, for instance, how individuals and partners worked together, to what extent there was agreement as to purpose, and the levels of reciprocity and trust. On the other hand, the researchers identified just four studies that specifically considered whether partnership-working had made a difference to the people using services and on the outcomes (see next section for discussion of outcomes) for individuals, with one study focusing on both processes and outcomes. Moreover, Dowling et al. (2004, p. 312) noted that even in

the studies that explicitly investigated whether partnerships had produced successfull outcomes, 'the results were ambiguous'.

One such study was Brown et al.'s (2003) evaluation of two integrated co-located[16] health and social care teams in a rural county of south-west England. Brown et al. (2003) used a non-randomised comparative design to compare outcomes for a user group served by two new integrated health and social care teams with those for a group of patients served by more 'traditional' arrangements over a period of eighteern months. The researchers noted that the co-located integrated teams – of primary carre and social care staff – were based in a GP practice and in a health centre (attached too a GP practice), with the comparison site consisting of a Social Services Department (SSD) team and a separate team of district nurses attached to a GP practice.

Brown et al. (2003) explain that the study sample comprised people aged sixty-four and over (registered with one of the GP practices taking part in the research) who were referred to the SSD for a community care assessment between July 1999 and June 2000, with the study only including those people who subsequently received am assessment for community care services. Noting that the integrated teams claimed that joint-working could facilitate earlier intervention (and thereby prevent emergency admissions to a residential/nursing home) the researchers explained that the main outcome-measure used was the proportion of people who remained living independently at eighteen months from the initial referral date. This, alongside speed of response from the referral to assessment, was used with the whole sample (n= 393). Additionally, the researchers used secondary outcome measures with a sub-sample of service users who agreed to be interviewed. Semi-structured qualitative interviews (n=207) were carried out with people using the new integrated teams (n=109) and the traditional teams (n=98) during which issues relating to the secondary outcome measures were covered in addition to more general discussion regarding service users' experiences and satisfaction with the process of asking for and receiving help.

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[16] According to the British Medical Association (BMA, 2012, p. 6), co-location is a process of, 'professionals from different organisations being located in and potentially working together from the same place to offer a common service'.

Contrary to expectations, Brown et al. (2003) reported that less (rather than more) of the group of people using the integrated teams remained living independently after eighteen months compared to the group using traditional teams. The researchers pointed out that there were no discernible differences between the two groups as regards systems and outcomes measures pertaining to: contact with social services, visits made by a district nurse, functional ability and mental functioning. The researchers also noted that whilst the speed of response from referral to assessment was faster for the group served by the integrated teams, people from this group more often reported depression as well as scoring lower for Quality of Life. Moreover, Brown et al. (2003, p. 92) reported that:

> The qualitative part of the interviews did not reveal any major differences
> between the groups in relation to their experience of asking for help or their
> satisfaction with the services which they received.

A number of subsequent UK studies have reported similarly mixed findings in terms of the effectiveness of integrated working (for instance, Kharicha et al., 2004; Townsley et al., 2004; Davey et al., 2005). In a similar vein, in the evaluation of the English Department of Health's Integrated Care Pilots (RAND Europe and Ernst and Young 2012) the researchers noted that fifty-six per cent of staff who completed a questionnaire felt that care for their patients had improved as a result of the pilot, with staff interviewees also reporting that they believed that their patients were receiving better care. However, whilst the researchers noted that service users reported better co-ordination of care following discharge from hospital and the increased use of care-plans, fewer reported that their doctors or nurses involved them in decisions about care, that their views were taken into account or that they were able to see their preferred nurse.

Nevertheless, researchers of a number of local projects across the UK claim that these have made important steps towards integrated working. These include projects in Torbay (Thistlethwaite, 2011); Barking and Dagenham (Wistow and Waddington, 2006); Sedgefield (Hudson, 2006a; 2006b); Castlefield (Lyon et al., 2006); South Devon and Torbay (Sonola et al., 2013a); Bexley, Bromley and Greenwich (Sonola, et al., 2013); and Pembrokeshire (Thiel et al., 2013). Furthermore, a number of international studies are frequently cited as having provided evidence to support the integration of health and social care (Curry and Ham, 2010). Some of these I

referred to in Chapter One (see section, 'Improving the care of people living with chronic conditions: the importance of integration'). Additionally, Kodner (2009a) refers to the success of the *Program of All-inclusive Intensive Care for the Elderly* (PACE) and *Social Health Maintenance Organisations* (SHMOs) in the U.S., whilst notable projects in Francophone Canada are the *Système de Services Intégrées pour les Personnes Âgées en Perte d'Autonomie* (SIPA; see Béland et al., 2006) and the *Program on/of Research for Integrating Services for the Maintenance of Autonomy* (PRISMA; see Hébert et al., 2005; 2008).

Rosen et al. (2011) conducted case studies of four organisations integrating health and/or social care across different providers, comprising: a government-funded network to improve access to/quality of Medicaid services in North Carolina, U.S.; an independent practice association in New York, U.S.; an organisation providing support to GPs to deliver integrated care for people living with diabetes and other chronic conditions in Maastricht, the Netherlands; and a health and social care partnership in North Lanarkshire, Scotland. Rosen et al. (2011) explain that data were collected through document analysis and semi-structured interviews with senior executives, clinicians and managers from each organisation. The researchers reported that between nine and fifteen interviews were conducted at each site (no site-specific details were provided).

Rosen et al. (2011) explain that the interview-guide used open questions regarding: how interviewees understood integration; the goals that the organisation was pursuing through integration; and the factors that supported or hindered integration. The researchers included specific prompts regarding: the influence of factors internal to the site; data and information systems; financial and non-financial incentives; governance arrangements; leadership; the characteristics of teams and individuals; and the characteristics of the wider health system. Rosen et al. (2011, p. 22) note that their research identified six, 'key ingredients for progress with information'. However, no information was provided *vis-à-vis* the impact on service users' care or their views on integration.

Referring to the greater interest shown in integrative processes than in outcomes (as with Rosen et al.'s [2011] study), Glasby and Dickinson (2008, p. 28) contest that

many claims made by health and social care partnerships regarding potential improvements for service users are, 'more faith than evidence-based'. With Cameron et al. (2012, p. 1) likewise reporting that, 'The evidence base underpinning joint and integrated working remains less than compelling', Perkins et al. (2009, p. 113) go a step further in suggesting that:

> ...in the case of tackling health inequalities and improving public health, partnerships hitherto have had only a marginal impact and, on the basis of the admittedly poor evidence available, the cure could be said to have failed.

Reflecting on fifty years of NHS and Local Government integration, Wistow (2012) draws attention to the limited evidence that shows its effectiveness. In a similar vein, Cameron and Lart (2012) note that whilst successive UK governments have set out an agenda of increased structural integration, there remains little evidence as to whether they have been successful in removing the barriers to joint-working. Indeed, whilst in the section 'Integration and service fragmentation' (see above in this chapter) I noted that evidence of care fragmentation was referred to in a report by the House of Commons Health Committee (2012), in the subsequent Government Response (Her Majesty's Government, 2012, p. 2) it was indicated that, 'Integration can deliver real benefits to service users but progress achieved over the years has been limited and continues to be disappointing'.

At the same time, there is limited high-quality evidence of the impact of any model of integrated care for people living with chronic conditions (Singh and Ham, 2006; Nolte and McKee, 2008) just as Ouwens et al. (2005) and Bodenheimer (2008) argue that evidence supporting the use of a variety of collaborative designs relating specifically to the care of people living with chronic conditions is inconclusive. Moreover, it has been argued that service user involvement in the design, commissioning and planning of services has been weak and variable (Wistow, 2005) or has been overlooked completely (Beresford and Branfield, 2006). Indeed, Beresford et al. (2005) note that in projects aimed at incorporating joint-working and client and carer involvement into service-delivery, there is evidence of departmentalism and widespread fear of dominance of a biomedical over a social model of care.

So, whilst McCray and Ward (2003) suggest that the future of integration is positive – especially since issues of hierarchy and interpersonal conflict have to some extent been addressed – they also concede that despite team leaders' faith and positive views of their teams, quality and fragmentation of services remain an issue. However, those who question the validity of partnerships have been seen as confrontational, divisive and lacking common sense (Clarke and Glendinning, 2002). Moreover, it is suggested that there is a tendency for researchers to focus on the *perceived* benefits of integration (Armitage et al., 2009). In a similar vein, Perkins et al. (2009, p. 101) contend that, 'partnerships tend to be viewed a priori as "a good thing"', just as Nolte and McKee (2008, p. 64) argue that collaborative practice has a, 'logical appeal'. Davies (2002) suggests that this popularity has been enhanced by a widespread belief in partnership working that began to establish itself in the UK's political consciousness following New Labour's 1997 general election victory, arguing that, 'It is easy to assume partnership generates added value in a political-ideological culture that assumes it will' (2002, p. 176). Having described how the belief in the benefits of integrated working contrasts with a lack of robust evidence, in the next section I explore the difficulties in assessing how integration can be measured.

Assessment issues

In the first section of this chapter, I explained that the case for integration appears to have been hindered by language issues. However, in their literature review examining the impact of partnership working in the UK, Dowling et al. (2004) note that the situation has been exacerbated by an under-developed approach to assessment and, 'the rudimentary state of the art of conceptualising, measuring and demonstrating the success of partnerships' (2004, p. 315). In a similar vein, Billings and Leichsenring (2014) suggest that, notwithstanding increased international research into integrated health and social care for people living with long-term conditions, challenges remain *vis-à-vis* the acquisition of robust comparative information that can enable judgements to be made regarding the best approaches to adopt.

Others note that collaborative initiatives are inherently long-term and ill-suited to experimental research methods (Houston, 2008). The situation is not helped, it is

argued, by the frequent involvement of many partners and different interventions amidst broader initiatives, where attribution of change to a specific element can be particularly challenging (Kreuter et al., 2000). Indeed, in a report into health inequalities by the House of Commons Health Committee (2009), attention was drawn to the inherent difficulties of isolating and establishing causal links amidst the many variables of complex collaborative interventions and the length of time needed to detect the effects of policy change. Accordingly, it has been argued that the lack of evidence is perhaps a reflection of the complexity of evaluation rather than failings *vis-à-vis* the impact of health and social partnerships, with Dickinson (2009, p. 157) positing that:

> One possibility, therefore, is that the lack of unequivocal evidence linking partnerships to service user outcomes might be an expression of this complexity, rather than a lack of impact *per se*.

Indeed, Dowling et al. (2004) point out that successful integration is conceptualised in different ways by different people, with Thomas and Palfrey (1996) suggesting that this mirrors the way in which an integrated service, by definition, involves multiple stakeholders with differing conceptualisations of success. This is reflected in the wide variety of methodologies and measurements – even for similar indicators and outcomes – that are used to measure integrated programmes (Kodner, 2009a). Whilst Kodner (2009a, p. 73) adds that this renders consistency in evaluation of integrated projects problematic, he also suggests that it is difficult to compare like with like when the best integrated care for older people involves 'finding specific solutions to local problems'. In a similar vein, Leutz (2005) contends that all integration is local, later adding (Leutz, 2009) that joint-working should be tailored to the objectives and mechanisms of the specific initiative.

However, in their literature review of joint-working in health and social care, Cameron and Lart (2003) found that evidence has largely failed to take the multiple perspectives of all of the people typically involved in integrated projects into account. For instance, whilst the researchers identified many studies that examined service-provider viewpoints, they found few that examined improvement in outcomes from the clients' perspective. Similar comments were made in Cameron et al.'s (2012) update of the 2003 review, with the newer version including fifty-eight

UK-based peer-reviewed evaluations of different models of joint-working across the health and social care interface published since 2000. According to Cameron et al. (2012, p. 16), one of the main problems of the research evidence of integrated working to date has been that:

> The voice of service users and carers remains largely absent. Their views are not routinely collected in evaluations, which makes it almost impossible to comment on the outcomes that matter to the people who use services.

This is despite the fact that Cameron et al. (2012) emphasise that the priorities of service-providers and national policy-makers may differ from those of service users, with the latter less interested in the configuration of services than in how their own needs are addressed. A failure to take such factors into account has been seen as a fundamental weakness in UK policy, with Petch et al. (2005) arguing that central government has frequently neglected to frame partnership policy in terms of the outcomes desired by service users. Indeed, rather than focussing on outcomes, it has been argued that there are many more studies of partnership and integration in health and social care that concentrate on assessing process (ICN, 2004; Glasby and Peck, 2005; Kodner, 2006; Dickinson, 2008; Glasby and Dickinson, 2008). In a literature review of partnership-working carried out by the National Primary Care Research and Development Centre ([NPCRDC], 2007, p. 2), for instance, it was noted that:

> Research focussing on 'outcomes' is very limited. Hence there is little to show, one way or the other, that partnerships have produced changes in health, services and carers' experiences.

In the review, it is explained that 'process' is how a partnership functions and 'outcome' is its impact on services, carers and health status. It is further explained that issues of process include partners' commitment, shared aims and inter-dependency, levels of reciprocity, trust and respect, financial and legal implications, accountability, leadership and management arrangements and that issues of outcome include service accessibility for clients, equitability of service distribution, efficiency, effectiveness or quality of services and improvements in the experience of staff who provide care (NPCRDC, 2007). Whilst outcomes-measurement does not relate exclusively to the experiences of clients and carers, it is nonetheless this

measurement that has been frequently neglected in research to date (Petch et al., 2007; Coulter 2006; 2012).

This is a curious situation, arguably, given the centrality of client perspectives in UK policy and guidelines relating to integration and the importance attached to the use of evidence-based practice (Rummery, 2002; Muir Gray, 2009). But debates concerning validity tend to focus on selective understandings of what constitutes sound evidence (Humphries, 2003). For example, Glasby (2011b) notes the traditional dominance of a healthcare model that is quantitative in approach and that favours experimental design. However, Glasby and Beresford (2006) suggest that research designs should be determined by the questions that need answering and argue, for instance, that the experience of those admitted to a mental health hospital is best investigated by qualitative interviews. Indeed, Cook et al. (2007) argue that this 'lived experience' must be considered in order to assess how clients and carers feel about services. The quantitative randomised controlled trial – long seen as the 'gold standard' of health care research – is therefore, it is argued, an inadequate measurement tool in the complex field of integrated care (Woodard, 2007).

Instead, Gilbert (2006) considers that in terms of measurement of outcomes, the 'gold standard' is only attainable by taking into account the perspective of clients, with Nies (2009) noting that the effectiveness of partnership working should be assessed against the extent to which it delivers quality of life. Nocon and Qureshi (1996) concur, adding that any other approaches are likely to be inappropriate. Telford et al. (2006) explain the central role of 'patient stories' in the delivery of appropriate care of people living with chronic conditions, with the individual experience of clients the starting point for developing sensitive, client-focussed systems of care. This, according to the CSIP/ICN (2006), is an integral component of the implementation of key drivers for change and improvement in services.

The development of a set of questions that could be used to measure service users' experiences of integrated care was the goal of King et al.'s (2013) five-phase study. The first phase was an evidence review focussing on literature describing key domains of integrated care. The second phase comprised four qualitative focus groups (conducted in Oxfordshire, England), two with people living with long-term

physical/mental health conditions (n=6 and n=7) one with people living with long-term mental conditions (n=3) and one with informal carers (n=9). King et al. (2013, p. 19) explain that participants were invited to describe their experiences of health and social care with specific reference to 'integrated care' or 'care co-ordination', and encouraged to elaborate on components of care that were important to them based on good or bad experiences. The third phase, King et al. (2013) explain, was a desk review of existing surveys and drafting of questions for testing, with the aim of identifying additional considerations to inform question development. The fourth phase was an 'owners' workshop' attended by representatives from national survey owners, with the aim of highlighting issues with the developed questions before cognitive testing. The fifth phase, finally, consisted of cognitive testing, with three rounds of testing carried out with patients, service users and carers. King et al. (2013, p. 6) explain that the study produced a set of eighteen recommended questions that could be used in national surveys to help providers and commissioners to, 'identify, explore, and challenge poorly integrated care locally'.

Despite such developments, Glasby (2011) contends that evaluative research in health and social care has been strongly influenced by method-led approaches derived from effectiveness studies carried out by organisations such as the Cochrane Collaboration and NICE. This is also true, it has been argued, for evidence-based policy making, where there has been a tendency for measurement based on a positivist worldview (Bate and Robert, 2003). Nevertheless, the position of primacy enjoyed by such long-standing approaches to programme evaluation has been challenged as ill-suited to real world research, with Pawson (2006) considering such methods to be purgative of context. Glasby and Beresford (2006) therefore argue for a more inclusive conceptualisation of evidence-based practice that takes account of the socio-cultural complexities and multiple perspectives involved in health and social care research.

This, Glasby and Beresford (2006) argue, should be based on the following four core assumptions: the best method for answering any research question is by using the most appropriate methods (rather than a pre-defined hierarchy); some questions necessitate proximity to the research subject (rather than the distance and objectivity associated, for example, with randomised controlled trials); the need to incorporate

as broad a range of material and voices as possible; the need to examine the experience of service users and carers and the knowledge-base of practitioners. Furthermore, alongside a limited number of controlled studies that identify which specific elements are effective in integration and long-term care (Nies, 2009), there has been a recognition that the study of integration is ill-served by current approaches to the measurement of the quality of processes and outcomes (El Ansari and Weiss, 2005; Dickinson, 2008).

Outcomes have been defined as the, 'impact, effect or consequence of help received' (Nicholas et al., 2003, p. 2). Viewed in these terms, they are the net result of all the actions of an organisation on a service user's experience. However, there is widespread recognition that measuring outcomes and examining the effects of health and social care interventions on those outcomes are complex tasks (Cheetham et al., 1992; Qureshi and Nicholas, 2001; Nicholas et al., 2003; Davey et al., 2005; Netten, 2011; Cameron et al., 2012). Moreover, Netten (2011) notes that what is meant by an outcome inevitably varies on the context and scope of what is under consideration. This is perhaps not surprising given that most services are characterised by: intangibility – they can be neither stored nor tested in advance; heterogeneity – consumers often have different priorities; inseparability – it is only in the interaction with clients that services are produced (Lewis and Hartley, 2001).

Some sociologists have argued that it is not necessarily possible to obtain objective measures in a research environment that is both dynamic in nature and subject to many extraneous influences (Guba and Lincoln, 1981; Strauss and Corbin, 1990). This perhaps explains how writers have interpreted quite differently the same integrated schemes. For example, the Command Paper *A Plan for Investment a Plan for Reform* (DH, 2000) included a case study of a partnership between Somerset Health Authority and Somerset County Council that created a combined Trust, the Somerset Partnership Trust (believed to be the first integrated health and social care organisation in England ([Glasby et al., 2010]). The partnership utilised a Joint Commissioning Board (JCB) to organise the care of people living with mental health problems. In the case study included in the government document, attention was drawn to the inclusive nature of the project and to the fact that all major stakeholders – including service users and carers – were represented on the JCB. As regards the

partnership structure itself, moreover, it was indicated in the government document that:

> The benefit for clients is that they have a single care plan, a single key or link worker and a unified multi-disciplinary team to deal with whatever health or social care need they have (DH, 2000, p.71).

However, Peck et al.'s (2002b) evaluation of the Trust's creation was more guarded in its conclusions. The study, carried out over a 30-month period, combined non-participant observation of JCB meetings; analysis of documentation (including meeting minutes); structured interviews with service users; focus groups with service users and their carers; a self-administered survey of all staff members involved with adult mental health provision; semi-structured interviews with senior managers of health and social services; and exploratory workshops with self-selected members of staff.

Peck et al. (2002b) reported that service users' and carers' initial hopes of full involvement in the JCB were replaced by a degree of disillusionment. Whilst one service user reported, for instance, that the agendas of JCB meetings were decided without prior service user/carer consultation – thereby restricting their input into the decision-making process – carers suggested that they were ill-informed and unrecognised as co-members of the care team. Although some service users recognised improved co-ordination within the multi-disciplinary team, this was felt to be compromised by a loss of therapeutic and support groups and the closure of buildings. Finally, whereas there was a general improvement in mental health status, the lack of control study made it impossible to conclude with certainty that this was as a result of integration. In a later appraisal of the research, Peck et al. (2004, p. 47) noted that:

> The establishment of the combined Trust did not appear, by the conclusion of the evaluation period in 2001, to have delivered any significant benefits that had not been delivered elsewhere in England without the transfer of social care staff to NHS employment. This is not to say that it did not achieve change (e.g. improved care co-ordination within co-located teams). However, there is no way of knowing whether comparable change would not have been achieved without the novelty of that application.

Arguably, the episode highlighted two important issues of research into integration in health and social care: the first was whether or not changes were due to the application of integrative practice or to outside factors that have been overlooked:

the issue of attribution; the second was whether or not specific changes were set out as a pre-defined goal at the outset of the project or were unforeseen: the issue of unintended outcomes. According to Petch et al. (2005) problems of attribution are frequently encountered because it is difficult to rule out extraneous factors. Safford et al. (2007) argue that this is particularly true in the care of people living with chronic conditions, especially in the community. The latter, Safford et al. (2007) point out, is an environment characterised by changing power relations and intricate social processes that easily confuse the link between cause and effect and in which, moreover, outcomes may not be obvious for many years. As for unintended outcomes, the difficulty of untangling potential contributory elements has been noted by Levin et al. (2002).

Levin et al.'s (2002) prospective study assessed the feasibility of comparing alternative approaches to integrated working between health and social care in the community setting, with the researchers comparing two mainstream health and social care collaborations for the care of people aged over seventy-five in two London boroughs. The researchers added an extra dimension by attempting to replicate the challenges of inter-agency working by making the research project itself a collaboration between two teams based at separate sites. Levin et al.'s (2002) study included several different methods of data collection: interviews with health and social care managers and practitioners (n=69) to assess joint-working arrangements and the training and support required for its development; systematic data collection of people (n=224) aged seventy-five or over (previously referred to the locality teams) with complex long-term care needs; baseline assessments of older people (n=79) divided across both areas in the community setting; interviews with main carers (n=47) to assess their physical and mental state and satisfaction with services; follow-up interviews with carers and clients after six months to evaluate satisfaction with services and outcomes; and analysis of methods to log and assess the health and social care input into care packages.

Whilst Levin et al. (2002) noted that there were challenges in comparing and measuring integrated health and social care services in the community setting at each stage of the research project, two examples provide an indication of the difficulties they faced. Firstly, the participation of health and social care professionals was not

consistent and frequently relied on individual goodwill. Social workers' participation, for example, was influenced by the enthusiasm and backing of senior or team managers. This was not the same for the managerially and professionally autonomous GPs. The absence of accountability to senior managers meant the latter alone decided whether or not to co-operate (both in the research project and in the integrated project itself). This varied according to interest-levels in and knowledge of older people's health issues, the support staff available in each practice, work-load, and the importance attached to closer working with social services. Secondly, existing computerised systems could not always provide necessary research information, Levin et al. (2002) reported. This reinforced the importance of co-operation at individual practitioner-level; it made the tracking of clients very time consuming, due to procedural differences in recording client-contact of GPs and social workers; it complicated collection and comparison of client information due to inconsistency in data collection and storage, plus differences in quality and content of logs across the various GP practices.

The researchers found the comparison of different strategies for integration to be complex, labour-intensive and time-consuming. Whilst Levin et al. (2002) reported that some information gained from the research was useful in its own right, they noted that service users' experience and the outcomes of services could only be explained partially without an in-depth and multi-faceted approach. Moreover, the varying degrees of health and social care professional participation had implications as to the extent to which structural change alone could improve services without an accompanying cultural change (a subject to which I return in the next section).

Comparing Levin et al.'s (2002) research with the development of the Somerset JCB, arguably, helps elucidate how outcomes depend on the interplay of many factors within a very complex setting. On the one hand, therefore, the Somerset partnership was deemed to have had limited success, without showing a categorical link between cause and effect (Peck et al. 2002b). On the other, it was held up as an example of good practice of partnership working leading to an improvement in outcomes (DH, 2000). But on closer inspection, arguably, what was praised in the government evaluation were those elements that related to the *process* of service delivery rather than the *outcomes* for service users.

In the last two sections I have discussed, on the one hand, the lack of robust evidence to show that integrated working improves outcomes for people using services and on the other, the inherent difficulties in assessing such outcomes. Whilst these discussions appear to be ongoing and unresolved, in the next section I explore some of those factors that are considered to help promote and develop integration.

The determinants of integration: structure or culture?

According to Goodwin and Shapiro (2001), integration is often considered in terms of the development of techniques and models to establish formal and informal collaboration between the health and social care sector, occurring at a number of different levels, including planning and policy making, funding, administration, and the provision and delivery of care itself. Glendinning (2003) refers to the existence of structural frameworks to facilitate integration, the Organisation for Economic Co-operation and Development (OECD)/European Commission (EC) (2013) to the use of multidisciplinary teams supported by case or care management and Leutz (1999) to the connection of health care systems with other human service systems. MacAdam (2008) notes that integration is frequently viewed as a way of reducing the fragmentation and duplication of care, inefficient services and wasted resources that result in poor outcomes for service users. In a similar vein, the literature from the last decade has witnessed a growing recognition that the ultimate goal of integration is to deliver quality of life to service users (Gröne and Garcia-Barbero, 2002; Nies, 2009; Goodwin et al., 2012) and to improve outcomes and people's experience of care (Goodwin et al., 2012; Coulter et al., 2013).

Accordingly, instead of organisations, services, budgets or professions, it is argued that the focus of attention of integration should be on the needs of service users (Humphries and Curry, 2011; Coulter, 2011). Alongside their informal carers, the need to increase service users' involvement in the process of integration has been highlighted by a number of commentators (Hiscock and Pearson, 1999; Nies, 2004; Curry and Ham, 2010; Barnes and Cotterrell, 2012; Coulter et al. 2013) and has been noted in numerous policy documents in Wales and UK-wide (WAG, 2009; 2010; WG, 2012; DH, 2004; 2007). According to Lewis et al. (2010), this places the service user firmly at the centre of the wider framework of integrated care. It is

therefore argued that the level, type and combination of strategies used to integrate services should correspond to the particular needs and challenges of those individuals receiving care (Veil and Hébert, 2008) with an awareness of the wider socio-economic factors that impact on wellbeing considered essential (Improvement and Development Agency/Audit Commission [IDeA/AC], 2006; Woodard, 2007).

However, despite many governmental exhortations for health and social care agencies to work together to improve service provision, the way in which this should be done remains unclear (Powell et al., 2001). On the contrary, just as Goodwin et al. (2012, p. 3) note that there is no 'best practice' model of integration, so Ham and Walsh (2013, p. 2) indicate that there is no 'best way' of integrating care. Notwithstanding, integration is often considered in terms of the development of specific techniques and models to establish formal and informal collaboration between the health and social care sectors (Goodwin and Shapiro, 2001). This can occur at a number of different levels, including planning and policy making, funding, administration, and the provision and delivery of care itself (Curry and Ham, 2010).

Rosen and Ham (2008, p. 2), for instance, explain that integration can be 'real' or 'formalised' using organisational mergers or 'virtual' using networks between different organisations with contracts or informal agreements. Alaszewski et al. (2003) explain that organisational integration can be considered in terms of vertical and horizontal levels. These are, respectively, integration between different components of a supply chain or integration between similar levels of care (Shaw et al., 2011). Alongside a number of other commentators (such as Curry and Ham, 2010, and Petch, 2014) Glendinning (2003) refers to three horizontal levels at which integration can take place, namely macro-, meso- and micro-level. Macro-level integration takes place within national or state ministries or county-level strategic-planning bodies, involving decisions that relate to resource allocation and investment; meso-level integration refers to the operational management of local service units or frontline teams; and micro-level integration is the integration of diverse elements of different services at the individual service user level (Glendinning, 2003).

Glasby (2003) considers integration of services in terms of the relationships that exist within and between different levels. He draws on his review of research studies focussing on hospital discharge to provide evidence of a number of recurrent problems. These include: a failure of health and social care professionals to work effectively together; a failure to involve clients and carers in ongoing care arrangements; the incompatibility of health and social care systems due to different professional cultures; and the existence of structural, organisational and professional barriers. According to Glasby (2003), these problems can be positioned in three separate but related categories, each requiring a different policy response. At the outermost level is the structural level integration existing between central and local government; following this is the organisational relationship between the local authority and the NHS; and at the innermost level is that between the client, carer and practitioner. Glasby (2003) considers that each of these levels depends on and is influenced by the others in a two-way movement. According to Poxton (2004) this makes management across these boundaries a fundamental issue in the drive for 'joined up' health and social care. This is reflected in the way in which researchers have examined integration in terms of individual, operational and structural levels or by focussing on horizontal and vertical integration, either within the same agency or between different ones (Edwards and Miller, 2003; Glasby and Lester, 2004; ICN, 2004; Komp et al., 2004; Fletcher, 2006; Glasby and Peck, 2006).

A number of commentators have used frameworks that categorise partnerships in terms of matrices or continuums of integration. Poxton (2004), for instance, refers to a sliding scale that moves from informal links through to full integration via increments of increasing collaboration. Poxton (2004) points out that there is a growing emphasis on partnership working which concentrates on users' pathways or journeys through the various care systems, the aim being to enable older people to stay in their own homes as long as possible, to make their hospital stays as brief as possible, and to help them remain as independent as possible. Poxton (2004) divides integration into four levels: informal communication between partners relating to their individual outcomes; more formal co-ordination, incorporating a recognised system of information exchange; collaboration, comprising joint-working but maintenance of separate identities; and full integration, with partners working together as one agency.

The AC (1998, pp. 17 – 19), similarly, provides specific details of the functioning of different degrees of collaborative initiative. At the least formalised level, prospective partners can initiate a 'steering group' that has neither specific staff nor budget allocated to the partnership, with service delivery made using each partner's mainstream programme and resources. At the next level, staff from partner organisations are co-located and work to a common agenda, albeit under separate management. Subsequently, there are 'virtual partnerships', in which a partnership adopts a new and separate identity, but lacks legal formalisation. It therefore has all the traits of a partnership, for example, co-located staff who are answerable to the partnership (which has a unique name and logo) but is formally managed by only one of the partners, who also employs all staff. Finally, there is the creation of a 'separate organisation' that has its own legal identity.

Peck (2002) describes a continuum for partnerships in graph-form, allowing potential partners to consider the balance they wish to strike between depth and breadth of relationship. The depth of relationship runs from information-sharing to formal merger (by way of consultation, co-ordination, joint-management and partnership). The breadth relationship runs from two partners (from health and social care) to health and local authority, and health, local authority and wider community. Peck (2002) specifies that this framework highlights the dynamic nature of partnership, with the possibility of repositioning partners (according to breadth or depth) as circumstances change and develop.

Nolte and McKee (2008) draw attention to a series of typologies, laws, classifications and dimensions that have been used to classify integration and to analyse different approaches. Wales' Health and Wellbeing Best Practice and Innovation Board ([HWBPIB] 2013, pp 5 – 6), for instance, notes that the 'key determinants of effective integration of health and social care' are: clarity of strength and purpose; collaborative leadership; a culture of learning and knowledge management; a supportive legislative/policy environment; integrated management structures; trust based interpersonal and interprofessional multidisciplinary relationships; appropriate resource environments and financial models; comparable IT and information-sharing systems; unified performance management systems; and collaborative capabilities and capacities.

In an overview of integrated care in the NHS, Shaw et al. (2011, p. 8), explain that 'five main types' of integration are frequently described in the literature of integrated working, namely: systemic, normative, organisational, administrative and clinical integration. Alongside each type of integration, Shaw et al. (2011, p. 7) describe their accompanying 'allied integrative processes'. Table 2 (below) sets out this relationship.

Table 2: Description of the five main types of integration and allied integrative processes (Source: Shaw et al., 2011, p. 8)

1. Systemic	**Co-ordinating and aligning policies, rules and regulatory frameworks** for example, policy levers emphasising better co-ordinated care outside of hospitals, central impetus for diversity of providers, development of national incentive schemes (for example, the Quality and Outcomes Framework) or financial incentives to promote downward substitution).
2. Normative	**Developing shared values, culture and vision across organisations, professional groups and individuals** for example, developing common integration goals, identifying and addressing communication gaps, building clinical relationships and trust through local events, or involving service users and the wider community.
3. Organisational	**Co-ordinating structures, governance systems and relationships across organisations** for example, developing formal and informal contractual or cooperative arrangements such as pooled budgets or practice-based commissioning; or developing umbrella organisational structures such as primary care federations or local clinical partnerships. (Continued overleaf)

4. Administrative	Aligning back-office functions, budgets and financial systems across integrating units for example, shared accountability mechanisms, funding processes or information systems.
5. Clinical	Co-ordinating information and services and integrating patient care within a single process for example, developing extended clinical roles, guidelines and inter-professional education, or facilitating the role of patients in shared decision-making.

Similar typologies are described, *inter alia*, by Fulop et al. (2005), Demers and Lavoie (2008), Lewis et al. (2010) and Valentijn et al. (2013). In addition to the five 'types' identified by Shaw et al. (2011) Ramsay and Fulop (2008, p. 11) add 'functional integration'. The latter, Ramsay and Fulop (2008, p. 11) explain, occurs when, 'non-clinical support and back-office functions are integrated'. Whilst Ramsay and Fulop (2008, p. 1) note that these six elements have been considered 'key requirements' for effective integration, they add that this does not mean that every sort of integration will be relevant to every sort of integrated project. Likewise, Shaw et al. (2011) report that the incorporation of specific elements reflects the stakeholders who are involved in a specific project and its goals and resources.

As illustrated in Table 2, one of the 'types' of integration described by Shaw et al. (2011, p. 8) is normative, or the development of 'shared values, culture and vision'. The relative importance of structural and normative features of integration has been widely discussed in the literature of integrated working (Robertson, 2011; Petch, 2014). Peck and Dickinson (2009) and Petch (2014) note that in discussions of partnership working between health and social care organisations, culture is a recurrent theme. Although Mullins (2013) points out that (organisational) culture has many different meanings, Schein (2004, p. 17) suggests that the culture of a social group (in which he includes organisations) can be defined as:

> ... a pattern of shared basic assumptions that was learned by a group as it solved its problems of external adaptation and internal integration, that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems.

Hudson has consistently argued that a key factor in achieving successful integration relates to the relationships between those who deliver and use care (see, for instance, Hudson, 2011; 2012). Hudson (2011) contends that despite repeated reorganisations of health and social care systems and the proliferation of policies to encourage partnerships, little progress in achieving health and social care integration has been made since the turn of the millennium in England. In order to address 'wicked issues', Hudson and Henwood (2002, p. 164) have argued for 'new partnerships' which, they contend, should be premised on: *understanding*, a recognition of the need to take account of a variety of viewpoints; *thinking*, based on holism, interactions and relationships; *working*, acceptance of different perspectives, approaches and styles; *involving*, a mentality of inclusion that draws on a wide variety of organisations and interests and is open to public involvement; and *learning*, the promotion of experimentation, diversity and reflection.

Many commentators argue that integration should be viewed as a combination of factors, with structural factors alone insufficient to ensure such success (Goodwin et al., 2012; Petch, 2013). Minkman (2012, p. 348), for instance, explains that the process of integration is often described as 'multifaceted in nature, requiring the integration of structures, processes, cultures and social relationships'. Kharicha et al. (2004, p. 135) note that: 'It appears that good working arrangements derive from the culture, skills and attitudes of the professions involved and are less likely to be the result of structural changes'. In order to examine the relative importance of structural and normative factors, it would seem useful to compare systems that have different levels of structural integration.

Helpfully, this can be done within the context of the UK, given that Northern Ireland has a more structurally integrated system than the rest of the UK (Timmins, 2013). Heenan (2013) reports that since 2007, Northern Ireland has had five fully integrated and fully comprehensive health and social care trusts. Each provider trust covers all primary acute and community health and social care provision, with one central

integrated commissioning body, the Regional Health and Social Care Board. Heenan (2013) notes that each unified trust has a number of key integrated features: it delivers all health and social care; it has 'employing body' status; it has a single financial system; and it has a single strategic approach with an agreed set of aims and objectives. Although the current structure in Northern Ireland dates from 2007, in 1993 it was already considered to possess one of the most structurally integrated systems of health and social care in Europe, having had highly integrated arrangements in place since 1973 (McCoy, 1993).

Heenan and Birrel (2006) conducted a qualitative study of structural and operational factors on the delivery of integrated care in Northern Ireland. At the time of the study (pre-2007), Northern Ireland had eleven Community Health and Social Services Trusts sharing a structure of nine integrated 'programmes of care' (Heenan and Birrell, 2006). These included mental health, physical and sensory disability and care services for older people, all delivered on an interdisciplinary basis. All professionals across the Trusts were employed by the same organisation, had the same source of funding, were co-located, and shared the same goals. Heenan and Birrell's (2006) study consisted of semi-structured interviews (n=24) and three focus groups (participants n=16). The interviewees comprised directors of social services from the boards (n=4), chief executives from the trusts (n=3), and directors and assistant directors from the trusts (n=17). Following the interviews, the focus groups were used to capture the views and opinions of those involved in the management of the delivery of care, including nurses, community nurses and social worker leads involved in integrated programmes of care.

Heenan and Birrell (2006) reported widespread conviction amongst health and social care professionals that integration at an organisational level was an appropriate way of providing care for clients with complex needs, with the perceived benefits of the system including a 'one-stop shop' (2006, p. 50) of co-ordinated health and social care by way of a single point of entry and key worker. The researchers also reported consensus that the co-ordinated approach helped avoid duplication, fragmentation and disorganisation in service delivery, whilst ensuring that vulnerable people did not have to navigate their way around the systems of different care organisations. Interviewees emphasised the client-focussed nature of the service, indicating that this

was facilitated by key structural features, including: a single care manager working across health and social care, thereby providing an overview of co-ordination and monitoring of service delivery and allowing the service to remain client-focussed; a single assessment system, with the co-ordination of assessments involving multiple agencies and professionals, thereby facilitating transfers from hospital to community and the sharing of information; a single budget, facilitating the move from institutional to community care and helping avoid arguments regarding payments and transferral of people across different budgetary systems.

Northern Ireland's integrated system has also been researched using quantitative methods, with Challis et al. (2006) using a cross sectional survey to make a direct comparison with England's care system. Two postal questionnaires were distributed to all English local authority social services departments (n=131) and Northern Irish Trusts (n=11), with response rates of 77% and 100% respectively. The first questionnaire considered care management arrangements for all adult service user groups, the second focussed on people aged over sixty-five. The questionnaires were completed by staff with responsibility for policy formulation or management of community based services in the respective agencies. The researchers used questions related to five 'core' management tasks to reflect the levels of integration within each system: case finding; assessment; care planning; monitoring; and review.

Challis et al.'s (2006) initial proposition was that England's division of health and social care provision should display significant differences from the structurally integrated Northern Irish system. The researchers posited that differences would be most apparent across the following three areas: the process of care (including multi-disciplinary working) and assessment/care planning; care management; and specialist services. By drawing on broad hypotheses regarding integrated services gained by way of a literature review, the researchers sought to test five propositions. The hypotheses were that, in comparison to the English system, health and care services in Northern Ireland should be characterised by: greater involvement of health care staff; a more integrated approach to assessment; a more differentiated approach to care management; a closer link between care management and specialist provision; and a more expansive specialist dementia service. Following data analysis, Challis et al. (2006) reported that across all five indicators there was

evidence supporting greater integration in Northern Ireland compared to England. The researchers concluded that the delivery of health and social care by a single organisation was a significant factor in enabling a more integrated approach to meeting the needs of vulnerable older people through assessment and care management arrangements.

Returning to Heenan and Birrell's (2006) study, however, the researchers also found that negative legacies of inter-professional and cultural differences persisted. For example, the researchers reported ongoing difficulties *vis-à-vis* the dominance of the medical model of care and the frequent diversion of funding away from social care to meet acute care needs. The researchers therefore considered that whilst structural changes had improved services, for integration to become reality involved the adoption of a shared vision, noting that, 'This culture must permeate all levels of service planning and provision in order to provide an integrated mindset' (2006, p. 63).

Similar findings were made in Øvretveit et al.'s (2010) case study of the creation of an integrated health and social care system in Norrtalje, a Swedish local authority area. The researchers examined documents (including the new organisation's administrative plans, and legal/procedural frameworks) and conducted two rounds of individual interviews with: the project's implementation officers (n=2); the project's Chief Executive Officer (CEO) and senior administrative officer; the administrative head of the 'political board'; politicians from the latter (n=2); one private care provider; and heads of health and social services operational units (number unspecified). Whilst the new organisation was launched in 2006, interviews were conducted in the spring of 2008 and the autumn of 2009, with questions related to: how the new structure differed from the old; what preparations were made to implement the change and what factors helped/hindered it; the new structure's impact on working procedures and service-provision and its impact on patient experience and outcomes.

Reporting that changes were hampered by inter-professional cultural differences and professionally protective practices (with regard to boundaries and autonomy), Øvretveit et al. (2010) noted that there were weak incentives to develop co-ordinated

care in the public health and social service system and that management underestimated the need for and lacked the time and resources to develop clinical level integration until after the first phase of macro-level integration. The researchers added that whilst the latter facilitated the development of integration, this could only develop further by way of working closely with clinicians to make changes at micro-level, with actions required to modify the specialised systems and cultures which the new organisation had inherited. This, the researchers stressed, required a significant investment in time. Øvretveit et al (2010) noted (as with so many studies) that it was not possible to ascertain if integration had improved client-outcomes or experiences. Whilst the researchers suggested that the likelihood that this would be achieved had been increased by the structural and procedural changes, they noted that in view of the time-investment required to develop micro-level integration, the expectation was that only after five years would improvements be discernible. Alongside the time-investment necessary to develop integration, one of the study's main messages for managers and policy makers, Øvretveit et al (2010, p. 119) stressed, was that 'both macro- and micro-integration are needed for better care coordination and outcomes'.

According to Ham and Oldham (2009), the importance of different determinants in integrated working was indicated by the experiences of the so-called 'early adopters' of the three flexibilities of the 1999 Health Act (introduced under Section 31) and Care Trust status. Glendinning (2003) explains that the Health Act (1999) flexibilities were introduced to facilitate joint-working between health and social services and the NHS, noting that this legislation was not a centrally defined prescriptive template, but facilitated adaptation to local circumstances through a number of flexibilities. These flexibilities, Glendinning (2003) explains, allowed for: the pooling of health and social care budgets for specific services; the delegation of responsibilities and service planning and commissioning to one lead organisation working on behalf of all the partners; and the integration of health and social services within a single organisational, managerial and employment framework. As for Care Trusts, Ham (2009) notes that these were first announced in the NHS Plan in 2000, with powers to create them included in the Health and Social Care Act in 2001. Ham (2009) points out that Care Trusts combined NHS and local authority

responsibilities within a single statutory NHS body, with local authority councillors on their boards.

The 'early adopters', explain Ham and Oldham (2009), were areas of England that were amongst the first to make use of the Health Act flexibilities and the opportunity to adopt Care Trust status. Ham and Oldham (2009) note that three early adopter areas were Knowsley, North East Lincolnshire and Torbay. Developments in the first two areas have been documented by Wistow and Waddington (2006) and in the latter area by Thistlethwaite (2011). Other areas that were early adopters were Barking and Dagenham (also documented by Wistow and Waddington, 2006), Somerset (documented by Peck et al., 2002a; 2002b; 2004) and Sedgefield (documented by Hudson, 2006a; 2006b).

According to Ham and Oldham (2009), the principal lessons learned from the experiences gained in Knowsley, North East Lincolnshire and Torbay were fivefold. Firstly, local history and context are important factors in developing integration, with different approaches required in different areas. Secondly, integration needs to begin with a focus on service users and the creation of a shared vision across different agencies for future development. Thirdly, integration requires leadership from the top. Fourthly, integration at the front-line of care delivery is key, for instance by bringing together community health and social care teams and aligning them with GP practices. As regards this fourth point, the researchers also referred to the importance of the co-location of teams, a single point of access and a single assessment process. The fifth lesson, the researchers note, is the importance of evaluation, with the value of the work of each area corroborated by external recognition.

Like Øvretveit et al. (2010), Ham and Oldham (2009) stress that structural factors alone are not sufficient to achieve integration, but that this also requires a considerable investment in time. Moreover, a number of the lessons identified by Ham and Oldham (2009) appear to tally with the principles identified by the NHS Confederation (2010, p. 10), namely that integration should be based on: outcomes not targets; cultures not structures; place not organisation; delegation not transfer of functions; and clinical and professional engagement. Having discussed some of the

determinants of integration, in the next – and final – section of this chapter, I consider patient and public involvement initiatives.

Patient and public involvement initiatives

Recent years have witnessed a marked increase in interest across the world in the involvement of service users and citizens in the design and delivery of health and social care (see, for example, Martin, 2008a; Coulter, 2012; Baggott, 2013). With this interest mirrored in the UK, Coulter and Ellins (2006) report that here, 'the term patient and public involvement (PPI) is often used as *shorthand* [my emphasis] to describe the processes by which members of the public can shape service development'. Andersson et al. (2006, p. 9), likewise, report that in the NHS, 'the term PPI is used *loosely* [my emphasis] to refer to a range of initiatives and a number of ways of working that all share a commitment to involving the public'. Before providing a definition of PPI, I begin this section by discussing how this, once again, is a field that has been dogged by terminological issues.

Whilst the fundamental inter-dependency of involvement, integration and partnership working has been highlighted, *inter alia*, by Longley (2013) and by Baggott (2013), as with integration and partnership working – and as the above use of 'shorthand' and 'loosely' seems to suggest – PPI has been criticised for its lack of precision and clarity (see, for instance, Conklin et al., 2010; Renedo and Marston, 2011; Barnes and Cotterell, 2012; Beresford and Carr, 2012; Beresford, 2012; 2013; Carr, 2012; Mockford et al., 2012; Peckham and Willmott, 2012; Baggott, 2013; Dalton et al., 2014). Indeed, Albert and Passmore (2008, p. 11) note that the field is, 'littered with jargon', Forster and Gabe (2008, p. 334) indicate that there is, 'no consensus on terminology' amidst a, 'bewildering diversity of definitions' and Beresford (2012, p. 21) stresses that, 'terms tend to be poorly defined and carelessly used'. Hence, there are numerous reports that terms such as involvement, participation, engagement, empowerment and consultation are used inconsistently: sometimes synonymously, sometimes to denote fundamentally different phenomena (see, for instance, Anderson et al., 2006; Wait and Nolte, 2006; Moriarty et al., 2007; Robson et al., 2008; Mockford et al., 2012; Purtell et al., 2012).

Amidst the different definitions and perspectives, however, Adams (2008, p. xvi) considers involvement to be, 'the entire continuum of taking part, from one-off consultation through equal partnership to taking control' and participation to be that part of involvement, 'in which people play a more active part, have greater choice, exercise more power and contribute significantly to decision-making and management'. As for engagement, according to the King's Fund (2012, p. 4), this is the degree to which people are, 'empowered to be fully involved in their care, share in decision-making, and work with clinicians in meeting their needs'. As for consultation, this is defined by Participation Cymru (2011, p. 6) as a, 'formal process by which policy makers and service providers ask for the view of interested groups and individuals'. According to some (see Cook, 2002; Rowe and Frewer, 2005; National Voices, 2014) consultation is a weakened and passive form of participation in which professionals and statutory agencies retain control of (and power over) processes and outcomes and therefore often leads to little change.

When considering involvement in the provision of health and social care, Ong and Wood (2005, p. 250) point out that it is important to distinguish between the role of patients and that of citizens, explaining that the former is concerned with, 'personal rights and services' and the latter with, '"common good", collective provision and pooling risks'. In a similar vein, Coulter and Ellins (2006, p. 249) note that, 'patient involvement', on the one hand, 'is concerned with the contributions that people can make to decisions about their own treatment and care', and that 'public involvement', on the other, 'refers to the ways in which lay individuals can participate in decisions about the development, planning and provision of services'. Although Coulter and Ellins (2006, p. 249) recognise that there is 'considerable overlap' between patient involvement and public involvement – just as Florin and Dixon (2004, p. 159) point out that a 'spectrum of possible involvement' exists between them – they argue that a clear understanding of PPI has been muddied by a blurring of the distinction between the two.

Likewise drawing attention to the blurring of this distinction, Conklin et al. (2012) – in their systematic review of empirical research into public involvement in healthcare policy – suggest that this has led to confusion and lack of consistency in the way that involvement is theorised and conceptualised. Returning to Coulter and

Ellins (2006, p. 250), they argue that the frequently understood 'shorthand' meaning of PPI – one that is, they suggest, *inclusive* of public involvement in shaping service development but *exclusive* of patient involvement in the delivery of their own care – has only compounded the situation. But this has not stopped PPI from becoming, in the words of Coulter (2006a, p. 29), 'part of the everyday rhetoric of the NHS'.

Glasby (2012) explains that in the UK, widespread use of the term PPI followed the 1997 general election victory of New Labour. With many experts noting that from this time, ever growing interest was shown in PPI (see, for instance, Barnes, 1997a; Forster and Gabe, 2008; Renedo and Marston, 2011; Ocloo and Fulop., 2012; Armstrong et al., 2013), it has been called a, 'central component' (Vincent-Jones et al., 2009, p. 248) a 'central plank' (Andersson et al., 2006a, p. 3) and the 'cornerstone' (Hogg, 2007, p. 129) of the NHS under New Labour. Moreover, the subsequent election of the Conservative/Liberal Democrat coalition has seen no decline in this interest, argue Gibson et al. (2012, p. 531), who assert that PPI is now, 'firmly embedded in the policies of the Department of Health'. A comprehensive definition of PPI is provided by the Nottingham University Hospitals NHS Trust (2014, p. 5):

> PPI defines the way in which patients and the public have a voice in
> decisions about how healthcare services and research are planned, designed,
> delivered and evaluated. PPI must therefore operate on three levels:
> involving individual patients and their carers as partners in decisions
> about their treatment and care and empowering them to make informed
> decisions about their healthcare wherever practicable; enabling patients and
> the public to be involved and consulted on planning, monitoring, evaluating
> and developing services, proposals to change services and decisions about the
> way services operate; involving and engaging patients and the public in
> planning, development, delivery and evaluation of relevant research and
> research related activities to the benefit of patients and public.

As indicated in the last part of this definition, attention can be drawn to the use of PPI to denote involvement in healthcare research (see INVOLVE, 2014). Although my main focus of interest in this section is PPI as it relates to the design and delivery of healthcare services, my understanding of this field was enriched by a number of articles that I read on PPI in healthcare research. This was particularly helpful with regard to an issue that has been identified as a significant barrier to the development of PPI in both healthcare design and delivery and in healthcare research, namely the

95

lack of discussion – in empirical research – of the conceptualisation and theorisation of PPI.

Whilst I return to the conceptualisation and theorisation of PPI later in this section, even when used in the specific context of the design and delivery of healthcare services, Renedo and Marston (2011) draw attention to the failure of policy makers, healthcare professionals and lay participants to agree on an overarching definition, rationale or *modus operandi* for PPI. On the contrary, PPI has been described – by both Andersson et al. (2006a, p. 3) and the Joint Health and Social Care Regulators' Patient and Public Involvement Group (2010, p. 5) – as a, 'catchall term' and, in a House of Commons Health Committee (2007) report into PPI within the NHS, as a, 'nebulous and ill-defined concept, used as an umbrella term to cover a multiplicity of interactions that patients and the public have with the NHS' (2007, p. 10).

Commentators have referred to a lack of clarity, consistency and consensus – and concomitant ambiguity – pertaining to numerous facets of PPI. These include: the rationale, ideologies, philosophies, theories and concepts that underpin PPI (Fudge et al., 2008; Vincent-Jones et al., 2009; Staniszewska et al., 2011a; Foot et al., 2014); the aims and objectives of PPI initiatives (Anderson et al., 2002; House of Commons Health Committee, 2007; Dalton et al., 2014); the decision-making processes, strategies and methods used during the implementation of PPI initiatives (Crawford et al., 2002; Anderson et al., 2006; Walsh et al., 2012); the contribution of service users to PPI initiatives (Attree et al., 2008); the links between participatory initiatives and democratic representative structures (Beresford, 2012); the identify/role of those involved in PPI initiatives (Andersson et al., 2006; Coulter, 2011; Barnes and Cotterell, 2012; Beresford, 2013); the link between the context and processes of PPI (Anderson et al., 2002; Staniszewska et al., 2011a); feedback mechanisms used in PPI initiatives (Healthwatch England, 2013); and (measurement of) the impact and outcome of PPI initiatives (Staniszewska et al., 2011a; Mockford et al., 2012; Dalton et al., 2014).

Anderson et al. (2002, p. 20) contrast the prevailing lack of clarity that surrounds PPI with the 'rational ideal' of PPI initiatives, namely that these should begin with a clear definition of aims and objectives, proceed to the refinement of a clear approach

and thence to the implementation of an agreed plan using clear methods: the whole within a framework of careful monitoring and evaluation. But the researchers stress that the reality of most PPI initiatives, conversely, is that they are set against a backdrop of pre-existing initiatives, partnerships and networks that are populated by stakeholders with differing viewpoints, values, degrees of power and commitment. According to Anderson et al. (2002, p. 20), these factors render PPI, 'a messy business': so messy, they add, that the rational ideal of neat progression from aims through methods to outcome, 'almost never happens'.

On the contrary, Anderson et al. (2002) stress that those who try to adhere to the rational planning ideal are often frustrated by PPI's inherent contextual complexities. Drawing attention, instead, to the gulf that often separates planning from practice, Anderson et al. (2002) emphasise that organisers of PPI initiatives instead need to recognise that PPI equates to the accommodation of a diversity of interests, ideas and values, to the identification of common ground and to the negotiation of mutually acceptable solutions. Accordingly, the researchers advocate the adoption of an open-ended and exploratory stance to the design and delivery of PPI initiatives in which dialogue is ongoing and implementation – and its measurement – are subject to constant reconsideration. With this in mind, the researchers contend that the lack of clarity – and concomitant ambiguity – that surrounds PPI can, in fact, be seen as a positive attribute; positive, inasmuch as by allowing multiple interpretations of PPI, it fosters the accommodation and promotion of a range of perspectives. Others, however, maintain that such imprecision is a major barrier to the development of PPI (see, for instance, Brett et al., 2009; Staniszewska et al., 2011; 2011a).

The reported nebulousness, confusion and ambiguity that surround the field appear to have done little to dampen governmental interest in PPI across the UK. On the contrary, Tritter and Koivusalo (2013) argue that commitment to empowering individuals and communities to play a greater role in shaping health and social care services has assumed an increasingly prominent position in public policy discourse over the last two decades. Commentators stress that the growth in interest in PPI has been triggered by many different factors (Wait and Nolte, 2006; Naidoo and Wills, 2011; Conklin et al., 2010; 2012). For instance, it has been linked to: the influence of service user and patient rights movements (Barnes and Cotterell, 2012a; Brown et

al., 2012); a recognition that current methods of policy-making are no longer in tune with a public that is more educated and sophisticated but less deferential than in the past (Coulter, 2011; Baggott, 2013); an awareness that public participation can foster social capital[17] (Abelson et al., 2003); and a belief that encouraging people and communities to participate can improve their health and wellbeing or encourage them to assume greater responsibility for their own health or to develop their own initiatives (Wanless, 2004; Naidoo and Wills, 2011; Baggott, 2013).

In Chapter One (see sections, 'Health and social care systems under pressure: the need for change' and 'The Welsh CCM Model: integration, self-management, involvement, empowerment') I discussed the importance of involvement as it relates to the care management of people living with chronic conditions and its central position within the Welsh CCM Model. But it is perhaps worth reiterating that self-care and self-management render involvement particularly relevant (see also Davies et al., 2009; Battersby et al., 2010; Wellard, 2010; Coulter 2011; Coulter et al., 2013). According to Kralik (2010, p. 200) the major mechanism of policy change that will positively impact on people living with chronic conditions is therefore, 'the emergence and escalation of the agendas, priorities and values of consumers shaping policy'. The need to empower people living with chronic conditions to make decisions about their treatment has been highlighted by the Department of Health (2013) and by the Welsh Government (2014b).

Indeed, it is indicated in *Designed to Improve Health and CCM in Wales* (WAG, 2007, p. 34) that a key element in the establishment of the Welsh CCM Model is, 'the involvement and views of local people and of those living with chronic conditions'. But just as Coulter (2006a) draws a distinction between the concerns, interests and aspirations of patients and of the public, so she differentiates between the potential benefits of encouraging patient involvement, on the one hand, and of encouraging public involvement, on the other. Hence, Coulter (2006a) suggests that the former can help ensure appropriate treatment and care, improve health outcomes and safety, and reduce risk-factors ill-health, complaints and litigation; and that the

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[17] Putnam (1993, pp. 35 – 36) defines social capital as, 'features of social organisations, such as networks, norms and trust, that facilitate action and co-operation for mutual benefit'.

latter can help improve service-design, determine priorities for commissioning, manage demand, meet expectations and strengthen accountability.

Commentators have put forward a number of fundamental justifications for the use of PPI (Abelson et al., 2003; Martin, 2008; Baggott, 2013). It has, for instance, been linked to the need to render decision-making accessible to those previously excluded (Milliband, 2006) or the need to show the public value for money in spending decisions (Andersson et al., 2006). However, two basic rationales to justify PPI are frequently cited: from an ideological perspective, that it can increase the legitimacy of decision-making processes; and from a pragmatic perspective, that it can contribute to improvements in the quality of service provision (see Anderson et al., 2006; Barnes et al., 2007; Coulter, 2009; Heritage and Dooris, 2009; Martin, 2008; 2009; Vincent-Jones et al., 2009; Tenbensel, 2010; Baggott, 2011; Armstrong et al., 2013).

In terms of the legitimacy of decision-making, firstly, Tenbensel (2010) argues that when conducted in a democratic context, policy processes must be participatory in order to ensure transparency and accountability. In a similar vein, Ellins (2012, p. 189) refers to a, 'rights-based perspective' that advocates giving people a say in the services they use. Martin (2009, p. 310) suggests that participatory initiatives affirm the integrity of the connection between the public and public services, thereby contributing to the democratic renewal of society and addressing the issue of, 'democratic deficit'. The latter, according to Levinson (2007, p. 860) occurs when, 'ostensibly democratic organizations or institutions in fact fall short of fulfilling what are believed to be the principles of democracy'. This is of some note, arguably, given Glasby's (2012) assertion that a perceived democratic deficit within the NHS is a longstanding area of concern.

In terms of improvements in the quality of service provision, secondly, Tenbensel (2010) explains that this relates to the way in which public involvement can inform the development of policy. Martin (2009) argues that by engaging with communities on more equal terms, organisers of public services can draw on people's knowledge. Taylor (2007, p. 99), for instance, suggests that capturing the 'lay experience' of daily living with health or ill-health can help: identify behaviour and lifestyle

patterns (highlighting new areas for investigation); identify those factors that lead to health inequalities and influence health (enabling the adaptation of existing resources); identify ways in which people live and manage their lives; encourage interest and promote active involvement; and create mechanisms to allow dialogue/debate and to promote health-improvement programmes that are owned by the people. Ellins (2012) suggests that when seen in such 'instrumentalist' terms – as a means to better ends – involvement can be considered an important mechanism for ensuring the provision of health and social care services that are more accessible, targeted and responsive.

Ellins (2012) adds that the way in which PPI is justified has significant implications in terms of the criteria against which success is subsequently judged. Hence, she notes that when justified in 'rights-based' terms, on the one hand, the availability of opportunities for people to discuss issues and to share views and experiences is of paramount importance. But when justified in 'instrumentalist terms', on the other, she notes that the effectiveness will be measured against the outcomes that those opportunities produce. In the latter context, Ellins (2012) therefore stresses that the main issue of concern will be the extent to which involvement impacts on the quality and availability of services.

But the quality of the evidence-base for PPI – both in terms of the levels of service-user/public involvement and in terms of the subsequent effect on service-delivery – has been called into question by many experts (see Barnes and Coelho, 2009; Renedo and Marston, 2011; Mockford et al., 2012; Dalton et al., 2014). These include: Merrell (2009, p. 38), who notes that, 'there has been little research to date on how services are influenced by patient and public involvement'; Conklin et al. (2012, p. 1), who stress that, 'despite the growing body of work on public involvement in health-care policy, evidence of its impact remains scarce'; Tritter and Koivusalo (2013, p. 115), who contrast an extensive literature-base with, 'far less evidence of PPI on prioritization or commissioning of services'; Forster and Gabe (2008, p. 348), who note that PPI is characterised by a, 'striking lack of published evaluative research'; and Foot et al. (2014, p. 6), who report that although PPI is an established priority in UK health and social care policy, 'the evidence is clear:

overall, people are not as involved as they want to be in decisions about health and care'.

Similar remarks were made by Nilsen et al. (2007) in their systematic review of health care and 'consumer involvement' for the Cochrane Collaboration. Whilst at the time of writing of this thesis, the Cochrane Library contained no systematic reviews of PPI, Hunt (2004, p. 4) argues that there is 'little of note' to distinguish the latter term from the term 'consumer involvement' and that – alongside a number of other similar terms – the two are used interchangeably. In their systematic review, Nilsen et al. (2007) sought to assess and compare consumer involvement as it related to the following four areas: healthcare policy and planning (such as health technology assessment, consumer pay-back systems and inequalities in health care); clinical policies (such as clinical practice guidelines); patient information materials (specifically, those informing patients about personal healthcare decisions); and healthcare research (such as the design of clinical/epidemiological studies, identification of relevant outcomes or priority-setting).

Nilsen et al. (2007, p. 10) explain that their selection criteria was met by just five studies, comprising: two 'moderate quality' randomised controlled trials (RCTs) that showed that consumer involvement in the development of patient information material can improve clarity and knowledge; a further two 'moderate quality' RCTs that showed that the use of consumer interviewers rather than staff interviewers in healthcare research can result in (small) differences in satisfaction surveys; and one 'low quality' RCT that showed that the use of telephone discussions and face-to-face group meetings in priority-setting for community health can better engage consumers than mailed surveys.

Conversely, Nilsen et al. (2007) report that they were unable to identify any comparative studies of consumer involvement in the development of clinical practice guidelines. Moreover, whilst they explain that all of the studies included in their review evaluated involvement with consumers to assist in the development of healthcare policy, research or patient information, they add that none evaluated the involvement of consumers in the decision-making process. Accordingly, Nilsen et al. (2007, p. 10) conclude that this area remains largely unevaluated and that there is:

101

> ... a huge gap in the evidence from comparative studies about desirable and adverse effects of consumer involvement in healthcare decisions at the population level, or how to achieve effective consumer involvement.

Similar conclusions were reached by Mockford et al. (2012) in their systematic review of empirical research into the impact of PPI on UK NHS healthcare services. The researchers reviewed twenty-eight studies involving patients, carers or the public working either collaboratively with health care front-line professionals or managers (for instance, as lay members of NHS committees or in condition-specific groups) or as activity-leaders. The studies examined services in the fields of cancer, stroke, learning disability, community and mental health, as well as Primary Care Groups/Trusts and Primary Care PPI Forums. Methodologies comprised: case studies/reports (n=20); evaluations (n=5); secondary data analyses (n=2); and surveys (n=1). Methods of data collection included semi-structured questionnaires and telephone interviews, semi-structured and in-depth interviews, focus groups, non-participant observation of meetings and postal surveys.

On the one hand, Mockford et al. (2012) report that the reviewed studies contained numerous accounts of the positive impact of PPI on healthcare services across the three areas of service planning and development, information development and dissemination and attitudes of service users and providers. As regards service planning and development, firstly, Mockford et al (2012) note that improvements were reported in fifteen studies covering the following seven domains: the design of new healthcare buildings and their environment; the location of/access to services; the provision of additional services; the reorganisation of existing services; the organisation of acute trusts; systems of communication between health professionals and patients; and systems of communication between patients. As regards information development and dissemination, secondly, the researchers note that improvements were reported in ten studies covering the following three domains: the production of public and patient information; awareness-raising; and the development (or contribution to the development of) existing services. As for the attitudes of service users and providers, finally, the researchers note that, 'many studies' (2012, p. 35) reported the positive impact of service user involvement on attitudes, values and beliefs.

On the other hand, however, Mockford et al. (2012) indicate that the data collection methods used in the studies meant that these effects were captured, in the main, by way of descriptive reports and personal opinion, rather than by way of valid and reliable measurement tools. Moreover, the researchers point out that whilst the studies showed a marked variance in their levels of detail, they were uniform in their lack of description of service users (for instance, in terms of their age, ethnicity, work-situation or involvement in healthcare services), of how the latter were recruited or of the extent of their involvement in each PPI initiative. The researchers suggest that such inconsistent reporting, allied with the lack of valid and reliable measurement tools, militated against their ability to make objective assessments of the impact of the initiatives and to conduct cross-study comparisons.

However, Mockford et al. (2012) argue that this does not necessarily mean that the PPI initiatives had no effect, but instead denotes the difficulties of defining precisely what is meant by 'impact' in such a contextually challenging field. At a more fundamental level, the researchers suggest that this is a reflection of the fact that none of the studies provided an explicit definition of PPI and that all bar two failed to use theoretical arguments to elucidate their findings. As a consequence, the researchers point out that most studies lacked the necessary, 'conceptual and theoretical underpinning' (2012, p. 35) to develop a clear understanding of the impact of specific components or dimensions of PPI and to assess levels of conceptual equivalence across studies. This, despite the fact that the researchers stress that such detailed understanding is key to the development of a robust evidence-base that can, in turn, help policy makers and researchers further develop PPI initiatives.

Indeed, in their systematic review of the conceptualisation, measurement, impact and outcomes of PPI, Brett et al. (2009) point out that clear concepts and conceptualisations constitute the building blocks of theoretical models which can, in turn, provide a blueprint – once empirically tested – for the development of tools to evaluate specific concepts. However, Brett et al. (2009) note that formal conceptualising and theorising or the use of models or tools is uncommon in empirical research of PPI initiatives. In a similar vein, Staniszewska et al. (2011, p. 394) state – in a study that sought to develop a quality 'checklist' for PPI reporting –

that whilst there have been, 'some attempts to develop conceptual or theoretical frameworks', there is, 'no overall conceptual model of PPI impact that captures the essence of the concept and has been empirically tested'.

Accordingly, as regards the current landscape of empirical research, there appears to be some consensus that although there are numerous studies of PPI initiatives that claim to show increased levels of service user/public involvement and/or a concomitant rise in standards of service delivery, the majority comprise descriptive reports based on personal perspectives, with little use of valid and reliable measurement tools or theoretical models. As a consequence, it is argued that the way in which people have been involved or improvements achieved is difficult to understand and the contribution of specific elements difficult to isolate. In turn, it is argued that this lack of clarity militates against the accurate evaluation of impact, cross-study comparisons and the transferability of findings. In the words of Abelson et al. (2010, p. 18) the literature of participation is dominated by 'practice stories' that are 'heavy on contextual learning but light on causal mechanism', with much related empirical research conducted in a, 'theoretical vacuum'.

But that does not mean that the entire field of PPI operates within a theoretical vacuum. Quite the contrary, many theoretical models have been developed to help shed light on those factors which can inform participatory initiatives and provide the field with the necessary conceptual underpinning to promote further development (as noted, for instance, by Beresford, 2012; Glasby, 2012; and Baggott, 2013). Glasby (2012, p. 145) points out that these models are often portrayed in terms of a continuum that begins from a position in which the user/patient is a, 'passive recipient of services' and moves progressively to one in which services are, 'user-led'. Glasby (2012) adds that one of the best known and most influential of these models is Arnstein's (1969) 'Ladder of Citizen Participation'. The latter (henceforth Arnstein's Ladder) is, as Figure 2 (see overleaf) displays, set out as a hierarchical structure that moves from citizen 'manipulation' (at the bottom rung) to 'citizen control' (at the top rung) in increasingly participatory (and empowering) increments.

Figure 2: Eight Rungs on a Ladder of Citizen Participation. (Source: Arnstein, 1969, p. 217).
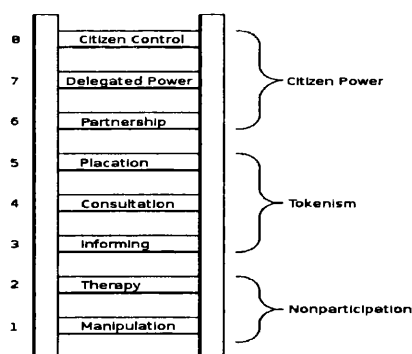
Anderson et al. (2002, p. 18), on the one hand, consider that Arnstein's Ladder can be seen as, 'a useful tool', arguing that even though its terminology is somewhat nebulous – the authors note, for instance, that 'partnership', is a, 'vague word which is used in many ways' (2002, p. 18) – it serves both to foster discussion and to encourage stakeholders to be, 'upfront about their expectations' (2002, p. 18). Tritter and McCallum (2006), on the other hand, question the continued relevance of Arnstein's Ladder, claiming that it has a linear and uni-dimensional format that is restrictive, that it conflates the means and ends of involvement and favours certain approaches over others (irrespective of context) and that it does not capture the dynamic and changing forces that impact on user involvement or the 'agency' of service users. Beresford (2012), in turn, contends that Arnstein's Ladder fails to take account of the complex, interactive and political aspects of public participation and of its susceptibility to manipulation (including that of citizens). With Beresford (2012, p. 24) adding that the same can be said of the 'derivatives' of Arnstein's Ladder, his remarks appear to be an allusion to those models that have conceptualised public participation by way of similarly hierarchical structures. These include Brager and Specht's (1973) 'Ladder of Community Participation', Connor's (1998) 'New Ladder of Citizen Participation' and, more recently, NHS England's (2013) 'Ladder of Engagement and Participation'.

Other models of public participation, whilst expanded to pay greater heed to contextual factors, have retained hierarchical structures. Examples include Charles and DeMaio's (1993) 'Dimensions of Lay Participation in Health Care Decision Making' and Wilcox's (1994) 'Framework for Participation'. Still other models contain no hierarchical structures at all. Examples include: South Lanarkshire

105

Council's 'Wheel of Participation' (Davidson, 1998) and its participation techniques which, it is argued, are 'transparent, inclusive and empowering' (1998, p. 14); Health Canada's (2000) 'Public Involvement Continuum', a model of involvement that purports to be cumulative and inter-dependent; Fung's (2006) 'Democracy Cube', which, it is suggested, represents the evolutionary and dynamic nature of participation and the diversity of citizens and their various roles and contexts; Tritter and McCallum's (2006, p. 165) 'mosaic analogy' which, it is indicated, captures the, 'interactions between individual users, their communities, voluntary organisations and the healthcare system on which successful user involvement depends'; and NHS England's 'Engagement Cycle' (NHS Institute for Innovation and Improvement, 2012) that comprises five-stages of patient and public involvement in commissioning decisions, from the identification of needs and aspirations to patient and carer engagement in monitoring services.

Despite these developments, it is widely reported that Arnstein's Ladder remains an important point of reference for those involved in participatory practice in health and social care (see Tritter and McCallum, 2006; Beresford, 2012; Glasby, 2012). This is evidenced by the inclusion of an Arnstein Ladder-influenced, 'Ladder of Engagement and Participation' in a recent guide to PPI and the English NHS (NHS England, 2013). Merrell (2009, p. 36) claims that nowhere is the continued relevance of Arnstein's Ladder better illustrated than in the UK's 'questionable' history of power-sharing between service providers and service users, particularly with regard to society's most disadvantaged people – like those living with chronic conditions – whose multiple and complex needs render them particularly reliant on many different health and social care services. In its 'PPI Good Practice Handbook', the Joint Health and Social Care Regulators' Patient and Public Involvement Group (2010, p. 33) notes that it is the very absence of disadvantaged people from many discussions pertaining to the development of services that makes them one of society's, 'seldom-heard groups'. The latter, Morrow et al. (2012, p. 107) explain, are made up of, 'under-represented people who use or might potentially use health services and who are less likely to be heard by service professionals and decision-makers'.

In a research project undertaken to inform the development of a practical guide to service user involvement for the Shaping Our Lives National User Network[18], Beresford (2013) sought to identify why it is that the voices of some service users are seldom heard and how the situation might be improved. The project comprised: the establishment of a steering group of service users to help guide the research; a collaboration between the report's research team and four local service user organisations that work with disadvantaged groups[19] (to identify which service users were missing from these groups, what the barriers to their involvement were and how these could be overcome); a national survey of service users' experiences of involvement in the development of health and social care services using a semi-structured interview questionnaire (respondent n=130); two group discussions with service users who face particular problems of exclusion (approximate n=100); and a comparison of findings with the views of other experienced service users from the Shaping Our Lives National User Group.

In the report, Beresford (2013) points out that a wide range of people are routinely under-represented during the development of health and social care services, including older people and those living with chronic conditions. Beresford (2013) explains that those people living with chronic conditions and older people who participated in the project, moreover, listed a number of structural and physical access barriers to their involvement in the development of health and social care services. These barriers included: a lack of accessible transport; inaccessible signage; lack of 'flat access'; inappropriate seating; unsupportive and hostile receptionists; inappropriate timing/unsuitable length of meetings; buildings that were difficult to access and inappropriate seating.

Beresford (2013) notes that one of the messages that emerged from the research project was that participants felt that such barriers reflected the low worth and low value attached to their perspectives. But he argues that little has been done to improve the situation and that there has instead been a, 'widespread failure to

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[18] An independent user-controlled organisation, think tank and network. See
http://www.shapingourlives.org.uk/
[19] The four groups comprised: a black and ethnic minority mental health service users group; a self-advocacy group of people with learning difficulties; a support group of women with alcohol problems; and a mixed service user group of people who use a variety of health and social care services.

encourage and support their [i.e. older people's] involvement' (2013, p. 21). He adds, moreover, that the voices of those with complex and multiple needs often remain unheard because of, 'unevidenced assumptions that they are not able or interested in being involved' or because they have been labelled, 'difficult' or 'awkward' (2013, p. 8). This is despite the fact that Beresford (2013) notes that access is a human and civil rights issue, inasmuch as any failure to meet the access needs of service users is tantamount to a denial of their right to full and equal participation in society.

Furthermore, participants referred to the negative impact of many other factors, not only on their ability, but also their willingness to participate. These included: the limited opportunities, multiple difficulties and lack of support that characterise their day-to-day lives and the concomitant low levels of confidence, self-esteem and expectations; the stigma associated with their specific service user identify and the perception that this would be reinforced by coming forward to participate; a devaluing of the service user perspective compared to that of people considered 'conventional "experts"' such as health and social care professionals and academics (2013, p. 34); and the reluctance of service providers to cede power amidst a 'tokenistic' approach to involvement that amounted to little more than, 'ticking boxes' or a, 'publicity-exercise' (2013, p. 34). Collectively, Beresford (2013, p. 35) explains, these barriers and issues had left many participants feeling, 'disempowered, disillusioned and disappointed'.

But similar barriers and issues have been listed in many reports that have examined the experience of service users/patients and/or the public during the development of health and social care services (see, for instance SCIE, 2007; Joint Health and Social Care Regulators' Patient and Public Involvement Group, 2010; Williamson, 2012). This, despite the longstanding awareness – which significantly pre-dates the appearance of the term PPI – of the key role these people can and should play in this process (see, for instance, Coulter, 2011; Baggott, 2013). Indeed, frequent reference has been made to the emergence – during the 1960s and 1970s – of independent service user and patient organisations and of statutory initiatives that were premised on increasing levels of participation (see Wait and Nolte, 2005; Greener, 2009; Beresford et al., 2011; Coulter, 2011; Tritter, 2011; Barnes and Cotterell, 2012;

Tritter and Koivusalo, 2013; Foot et al., 2014). Since it is beyond the scope of this thesis to examine both areas, I instead focus on statutory initiatives and, more, specifically, Community Health Councils (CHCs).

Established in 1974, Hogg (2009) explains that CHCs were established – alongside similar statutory bodies in Scotland and Northern Ireland – as the patients' watchdog for the NHS in England and Wales. According to Greener (2009), CHCs constituted the first concerted attempt organisationally to improve services to patients, created as they were in the wake of mounting censure of the NHS for its doctor-centred, paternalistic, over-medicalised and impersonal care. With Forster and Gabe (2008, p. 335) likewise drawing attention to an NHS culture characterised by a, 'paternalistic approach' in which little heed was paid to, 'the interests of users and citizens', they add that by creating CHCs, the objective was to give patients a voice in the NHS both individually and collectively: at the individual level, to assist patients who wished to complain about their care; and at the collective level, to monitor local health services, to inform the public and to consult on local health reorganisations.

But describing the introduction of CHCs as a, 'first tentative attempt' to develop involvement, Forster and Gabe (2008, p. 235) note that amidst criticisms of their lack of statutory powers, limited financial and staffing resources and inconsistent standards, many felt that their impact on the prevailing NHS culture was limited. With Barnes and Cotterell (2012, p. xv) drawing attention to the CHCs', 'ambiguous position *vis-à-vis* their insider/outsider position within the National Health Service', Baggott (2013, p. 99) adds that whilst CHCs made 'great efforts' to involve local communities, their democratic legitimacy was called into question. The House of Commons Health Committee (2007), moreover, drew attention to reports of CHCs' limited responsibility to primary care, insufficient independence and of a membership lacking in diversity (in terms of both age-range and ethnicity).

As a result of these and other issues (in particular, the advent of the internal market) Baggott (2013) explains that the 1980s and 1990s witnessed a growing tendency for NHS bodies to bypass CHCs altogether, with public opinion instead gauged and policies legitimised by way of surveys, focus groups, patients' and citizens' forums

109

and consultation exercises. Furthermore, Coulter (2011, p. 167) argues that in the absence of formal procedures for election to CHC boards, CHCs were heavily reliant on the energy and commitment of unpaid volunteers and a, 'very small number' of paid staff and that their roles were effectively, 'undermined by successive waves of policy innovation' (2011, p. 167). Consequently, Coulter (2011) explains that CHCs were abolished in England in 2003.

In England, the abandonment of CHCs was followed by the launch of a number of new initiatives, some of which, in turn, have been abandoned. As for the Welsh NHS, conversely, CHCs have remained in place since their 1974 inauguration. Vincent-Jones et al. (2009) explain that this was one of a number of significant differences between Welsh and English PPI policy to emerge in the post-devolution era (in contrast, the researchers add, with the broadly analogous approaches during the 1990s). With Hughes et al. (2009) indicating that these differences have crystallised around issues of 'choice' and 'voice', Le Grand (2007) explains that in the choice model, first of all, services are selected from competing providers, with choices including where, how and by whom treatment is provided and how relevant information is communicated. Andersson et al. (2006) explain that patient choice has been justified on the grounds that it promotes patient-focused care, is the logical extension of informed consent and is a mechanism for redressing the power inequality between health professionals and patients.

But Andersson et al. (2006) add that PPI has also been viewed as a means of promoting collective patient voice. Hughes (2009) explains that voice equates to the right to be informed, express views and be understood, Thompson (2007) that it involves collective freedom to achieve inclusiveness through a developmental process of engagement and Le Grand (2007) that it is a communicational process in which public service users transmit their views to public service providers. Hirschman and the American Council of Learned Societies (1970, p. 30) define voice as, 'any attempt at all to change, rather than to escape from, an objectionable state of affairs'. According to Greener (2007), implicit in the notion of voice is the right of citizens to participate in public services and change them by way of the political process or through direct involvement in their running.

Vincent-Jones et al. (2009) explain that post-devolution Wales has rejected market reforms and economic regulation and instead opted for PPI policies that promote public representation and provide opportunities to air the collective voice. With Hughes et al. (2009) suggesting that this trend has been consistent with Wales' post-devolution focus on citizenship, public engagement, mutualism, localism and partnership-working, these comments are, in turn, consistent with Birrell's (2009) indication that citizen-involvement in decision-making was central to the Welsh Assembly's new direction in health and social policy (see Chapter One, section 'The Welsh CCM Model: integration, self-management, involvement, empowerment'). With the importance of PPI emphasised in numerous Welsh policy documents published during the 2000s (see, for instance, Wanless, 2003; WAG/NHS Wales, 2005; WAG, 2006a) as well as in more recent strategies related to both health care and social care (WG, 2014b) Hughes et al. (2009, p. 245) assert that the Welsh Government has put a, 'distinctive stamp on PPI policies by developing a focus on citizen voice and engagement, while rejecting the consumerist market model'. Instead, note Longley et al. (2012a), the *views* of patients in Wales have been prioritised by way of the internal mechanisms of Local Health Boards and CHCs.

However, the transparency and understanding of a number of elements pertaining to the organisation and functions of Welsh CHCs have been questioned in recent reports. These include: a Welsh Government (2014c) review of governance and delivery in the devolved public sector in Wales, in which it is indicated that there is a need for CHCs, LHBs and Trusts to, 'clarify their respective roles and actions in public engagement' (2014c, p. 141); Lloyd's (2014) review of NHS Wales service-change engagement/consultation exercises, in which she notes that there is 'confusion about the role and responsibility of the Board of CHCs' (2014, p. 29) and that, 'the accountability of CHCs needs clarification' (2014, p. 34); and Evans' (2014) review of the handling of concerns/complaints by NHS Wales, in which he reports that, 'for the public, the role of CHCs in respect of complaints support is not properly understood' (2014, p. 52). In Longley et al.'s (2012) Welsh Government-commissioned review of the impact of the 2010 CHC reforms, moreover, the authors draw particular attention to the lack of consistency and clarity in the conceptualisation of the purpose and function of CHCs, emphasising that, 'doubt

remains in some areas about what is *really* [original emphasis] required of CHCs, and therefore about how they should perform their role' (2012, p. 19).

In addition to noting the uncertainty *vis-à-vis* CHC roles and functions, Longley et al. (2012) draw attention to a number of additional problems pertaining to the organisation and performance of Welsh CHCs. These include: inconsistency of performance (with substantial variations in how CHCs discharge responsibility); lack of diversity and representativeness (with membership described as, 'disproportionately white, older and middle-class' [2012, p. 6]); low levels of public knowledge/understanding of CHCs; sub-optimal discharge of the National Board of CHCs' leadership of the internal development of CHCs/representation of the collective voice of patients and the public; and unsystematic involvement in the NHS-funded services provided by registered nursing homes. With Longley et al. (2012, p. 6) describing these as, 'persistent weaknesses', they point out that amidst longstanding concerns about many aspects of Welsh CHCs' organisation and performance, these had already been areas of priority at the time of the 2010 reforms of CHCs.

In their recommendations to the Welsh Government to improve the organisation and performance of CHCs, Longley et al. (2012, p. 102) put forward a number of measures to address these 'persistent weaknesses'. However, in view of the prevailing lack of terminological/conceptual transparency to which I have referred throughout this section – and, indeed, throughout this chapter – it is of particular note that a number of these so-called 'weaknesses' relate directly to the lack of clarity and consistency *vis-à-vis* respondents' understanding of the role and function of CHCs and of the low-levels of public knowledge/understanding of CHCs. At the time of writing of this thesis, the Welsh Government had accepted the majority of Longley et al.'s (2012) recommendations and set out its response in the Consultation Document *Community Health Councils in Wales: Proposed Changes* (WG, 2014d). It therefore remains to be seen to what extent the many proposed actions that have been set out to increase clarity and understanding surrounding CHCs will be taken forward. Having discussed PPI initiatives, I end this chapter with a brief summary of the themes discussed.

Summary

I began this chapter by setting out my literature search strategy. I then examined the language of integration, explaining that despite a lack of clarity as to its meaning, there is some consensus that its organising principle should be the service user's perspective and that its ultimate aim should be to improve client care. Subsequently, I described the widespread agreement that integration is a potential answer to fragmented health and social care provision, before exploring evidence-based practice and implementation research. Whilst I subsequently discussed the lack of evidence that integration leads to improvements in care, I explained that researchers have encountered difficulties in assessing integration amidst discussions as to what precisely should be measured in order to gauge its effectiveness. I then reviewed some of the frequently identified determinants of integration and explored the relative importance that researchers have attached to structural and cultural elements of integration. I concluded the chapter by exploring PPI initiatives. In the next chapter, I discuss the methodology and methods I used in the case study of the development of the new CCM service.

Chapter 3: Methodology and methods

Introduction

Having conducted a review of the literature of integrated working in the previous chapter, in this chapter I discuss my chosen research methodology of case study and the methods I used to collect data. I begin by restating the aim and objectives of the case study, before describing my research approach and linking this design choice with my interpretevist stance. Subsequently, I discuss the research design, examine issues of access and sampling (including ethical approval) and the selection of the 'case' of the case study. I discuss the four methods of data collection I used (and whose I chose them), describe my subsequent handling and analysis of data and conclude by setting out the measures I took to ensure rigour.

Aim and objectives

My aim in conducting the research was to answer the question: How has integrated care for people living with chronic conditions developed during the implementation of the new CCM service? My objectives, in turn, were to answer the following five sub-questions:

1. How have different stakeholders been involved in the establishment of the new CCM service?
2. What do the stakeholders involved in the establishment of the new CCM service say about integration?
3. What do people living with chronic conditions and their carers say about the new CCM service and the care they receive?
4. What do front-line health and social care professionals say about their work in the new CCM service compared to their work in their previous teams?
5. How has the development of the new CCM service been affected by pre-existing services, roles and relationships and concurrent developments in health and social care?

Research approach

Commentators indicate that there is no commonly agreed definition of the term 'case study' (Hammersley and Gomm, 2000), that it is not used in a standard way (Hammersley, 2012) and that it has undergone changes in meaning over time (Ragin, 1992). The case study has been called, 'the study of the particularity and complexity of a single case' (Stake, 1995, p. xi), 'a study of a particular social unit or system' (Richards and Morse, 2013, p. 76), 'in-depth description and analysis' (Merriam, 2009, p. 4) and 'an empirical inquiry that investigates a contemporary phenomenon in depth and within its real life context' (Yin, 2009, p. 18). Whilst Richards and Morse (2013, p. 76) describe the case study as a 'method', it has also been described as, 'a way of organising social data' (Goode and Hatt, 1952, p. 331) and 'more a strategy than a method' (Punch, 2014, p. 120). There is, however, broad agreement that it is a way of providing an in-depth analysis of a naturally occurring single entity, or a small number thereof (Miles and Huberman, 1994; Stake, 2005; Denscombe, 2007; Silverman, 2010; Punch, 2014).

Just as there is no standard use of the term case study, so the case study is not the preserve of one methodology (Hancock and Algozinne, 2006) nor does it belong to a clearly defined methodological 'school' (Richards and Morse, 2013). On the contrary, Luck et al. (2006, p. 107) explain that the case study has been termed a 'paradigmatic bridge' between methodologies, with van Wynsberghe and Khan (2007) indicating that case study researchers have adopted a range of methodological approaches from post-positivism to critical theory. However, with its focus on a natural phenomenon over which the researcher has no influence (Yin, 2009) the focus of the case study is, it has been argued, social interaction (Hamel, 1993). Indeed, the case study is considered to be particularly well-suited to grappling with real life's intricacies and nuances (Denscombe, 2007) with Yin (2009, p.9) stressing that it aims to provide the answers to 'how' and 'why' questions of process, questions which are explanatory in nature and investigate operational links examined over time. Hence, Denscombe (2007) notes that whilst the case study is interested in outcomes, it is how these outcomes come about that is of primary importance.

Accordingly, note Richards and Morse (2013, p. 77), in case studies there is, 'almost always a commitment to qualitative techniques', with Hammersley and Gomm (2000) pointing out they often utilise qualitative data and analysis alone. Simons (2009) likewise notes that case studies often utilise qualitative methods only, with the aim of providing a detailed examination (and understanding) of the case in question. In a similar vein, my exclusive use of qualitative methods to chart the development of the new CCM service reflected my desire to focus on meanings, description, context and process (see, for instance, Becker and Bryman, 2004). Indeed, a number of commentators have made reference to the complexities of partnership-working in the care of people living with multi-factorial needs (Williams and Sullivan, 2009f; Glasby, 2012) just as others have noted that people living with chronic conditions face a complex combination of physical, social and psychological factors that impact on their lives (Field and Kelly, 2003). The impact of this combination of factors was recognised in *Designed to Improve Health and CCM in Wales* (WAG, 2007, p. 7), where it was stressed that amongst the concerns of people diagnosed with a chronic condition are:

> ...coping with fear, anger, frustration and denial, and also the effect the chronic condition is going to have on their job, relationships and perhaps other caring responsibilities.

Just as Charmaz (1983, p. 168) notes that the altered biographical trajectory of people living with chronic illness causes a, 'loss of self', she also indicates that this is best understood by way of a qualitative approach. According to Topping (2010), the philosophical tradition that underpins this qualitative approach is interpretevism. Topping (2010) explains that interpretevism is based on the assumption that in order to make sense of the world, human behaviours should be interpreted by taking account of interactions between people. This means, Topping (2010) adds, that research that seeks to understand human behaviour must employ approaches and techniques that allow interpretation in natural settings.

According to Bryman (2012), interpretevism subsumes a number of approaches to research which reject the application of the scientific model and positivist tradition to the field of social sciences including its *a priori* approach and theory-testing methods. The interpretive approach, notes Ransome (2013, pp. 63 – 64), aims to

generate theory from data, so that by starting out from the observation of individual cases, 'Theory is *induced* from the evidence rather than evidence being *deduced* from the theory [original emphases]'. Williams and May (1996) indicate that this inductive approach starts with a collection of data and moves to a general conclusion, involving the derivation of general principles from a set of specific observations. Accordingly, notes Rapport, (2005), interpretevism allows participants to give their own account of the world without the use of predefined measures, with Schwandt (1994) explaining that this provides an insight into the complex world of lived experience from the point of view of those who live it. Interpretevists consider that all knowledge – and therefore meaningful reality – is contingent upon human practices and is constructed in and out of interaction between human beings and their world and developed and transmitted within a social context (Golafshani, 2003).

Klenke (2008) notes that, according to interpretevism: human beings are not mechanistic and embrace multiple realities which need to be understood in context; the social world cannot be described without investigating how people use language, symbols and meanings to construct social practice; and no social explanation is complete unless it adequately describes the role of meaning in human actions. Moreover, Jones (1993) notes that interpretevism seeks to understand human social action by taking account of structural situations, motivation, and the element of choice in human behaviour, factors that are absent in natural science research. Accordingly, an underlying concept of interpretevism is *Verstehen*, an attempt to understand the social world from the perspective of the person being studied (Weber, 1949), a stance reflected in Liebow's endeavour to describe 'the life of ordinary people, on their grounds and on their terms' (1967, p. 10). Given my interest in examining how a wide a variety of stakeholders were involved in and experienced the implementation of the new CCM service, I felt that the natural epistemological stance to adopt was interpretevism, inasmuch as it is an approach that respects the differences between people and seeks to grasp the subjective meaning of social action (Bryman, 2012). In the next section, I provide further details regarding the decision to use a case study approach.

Research design

Flick (2009) explains that the 'case' of a case study is the focus of a process of precise description or reconstruction, with Creswell (1994, p. 12) noting that it is investigated within its natural environment and is, 'bounded by time and activity', so that it is self-contained with clear spatial and temporal margins. According to Merriam (2009), it is this concentration on the unit of analysis, not the topic of investigation, that characterises a case study (and therefore sets it apart from other types of qualitative research). Whilst I return to temporal margins overleaf, in terms of spatial margins, the case study restricts itself to the study of one naturally occurring entity (or a small number thereof) such as a person, village or firm (Gomm, 2009). There have been case studies of communities (Whyte, 1981), families (Brannen and Nilsen, 2006), organisations (Pettigrew, 1985) and events (Asmussen and Creswell, 1995). This concentration of the case study on the development of one natural phenomenon seemed to make this type of research suitable for my exploration of a new CCM service within in its 'natural environment' – a Welsh locality – and self-contained (or bounded) within the Armorshire Collaboration (itself contained with the National CCM Demonstrator Programme).

Hakim (1987) also suggests that case studies are well-placed to investigate organisational cultures, processes of change and the implementation and evaluation of policy. Simons (2009) adds that case studies examine the intricate and singular aspects of a particular project through close description, documentation and interpretation of events. This in-depth and multi-faceted approach seeks to capture how different stakeholders experience project implementation (Simons, 2009) and is essential in gauging service users' understanding of new services (Levin et al., 2002). Again, these features seemed to make the case study approach suitable for my aim, as I sought to explore the introduction of new CCM policy (by way of the implementation of the Welsh CCM Model), how the concomitant process of change impacted on a wide variety of stakeholders, and to gauge the extent to which the latter – in particular, service users and carers – were involved in the creation of the new CCM service. Moreover, given that it is widely agreed that organisational culture is a key factor in integrated working (Fulop et al., 2005; Shaw et al., 2011), the creation of the CCM service seemed to provide an ideal opportunity to examine

how front-line professionals had experienced leaving existing teams (and colleagues) to join a new team (and new colleagues) and how levels of partnership-working were affected by cultural and other factors.

In terms of temporal margins, case studies cover a specific time period, with data-collection often occurring simultaneous to events (Yin, 2009). Such 'real time' analysis is considered a particular strength of the case study, providing the immediacy and intimacy of a direct window onto contemporary events (Yin, 2009). These factors, arguably, made the case study approach a suitable match for my exploration of the creation of the new CCM service, as I set out to chart its development over the final two years of the Armorshire Collaboration's three-year existence and to research multiple stakeholders' experience of this process as it happened. Moreover, just as Fitzgerald and Dopson (2009) suggest that the flexibility of case study research allows it to cope with dynamic settings and thereby makes it well-suited for researching organisational change, so these characteristics seemed to make it all the more appropriate for researching the creation of an integrated service in the field of health and social care, given that the latter is considered especially 'context heavy' (Hartley and Benington, 2010, p. 4).

Indeed, issues of context are considered an integral part of case study research, which assumes that context is of great significance in understanding the phenomenon in question (Clarke and Reed, 2010). Stake (2005) notes that the qualitative approach to the case study concentrates on the detailed description of a complex entity (the case) as it is located in a particular social milieu and paying particular attention to its economic, political and cultural context. Contextual issues – and the flexibility of the case study approach in accommodating them – turned out to be of particular importance in my research. This was because the Armorshire Collaboration coincided with the 2009 NHS Wales Reforms, the 2010 UK general election victory of the Conservative/Liberal Democrat Coalition Government (and with it, the launch of a series of austerity measures) and the Wales-wide introduction of a new strategy, *Setting the Direction* (WAG, 2010). As I explain in the findings and discussions chapters, all three factors had a considerable impact on the Armorshire Collaboration's integrated agenda and the extent to which different stakeholders were able to become involved in the process of reconfiguring services.