

MENTAL HEALTH, PATIENT & PUBLIC INVOLVEMENT AND RESEARCH METHODS: INTERCONNECTIONS IN THE REAL WORLD

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Supporting commentary and a portfolio of selected papers for the award of Doctor of Philosophy

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April 2013

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Acknowledgements

My greatest thanks and gratitude go to my excellent supervision team - Professor David Evans and Dr Maz Morris. Your unrelenting encouragement, challenge and support was so much appreciated and overcame any publishing challenges.

Sincere thanks to colleagues, friends and family for their support and input at various stages of my research journey. Particular thanks for support and encouragement to my mother, Sheila Coe, and my grandparents, Florence and Harry Vowles. Thanks to Professor Harry Ferguson, a member of my supervision team for the first years, who encouraged my creativity. Thanks to Dr David Pontin for the chance conversation which set the whole thing off, and to Professor Dorothy Whittington for supporting me to register and for her ongoing encouragement. Thanks to Dr Anthony Harrison for being my 'DPhil buddy', for being a few steps ahead of me in the process, and for the mutual support and motivation. Thanks to Martin Carter for giving me permission to use the Somerset Health Panel data and to Jo Purvis who organised the logistics of the Somerset Health Panels and who became a lifelong friend as a result. Thanks to my husband, Matthew Williams for his unconditional love, support and encouragement, for his mastery of the English language and for his red pen. Finally, thanks to all the rest of my family and friends who have encouraged me along by asking how it was going every time I saw them over the last seven years. This work is dedicated to my father, Peter Coe, who I know would have been very proud.

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1. Overview

My submission includes a commentary (Section 3) and seven papers that I have published in peer-reviewed journals (Section 2, Appendix 1).

I have identified three main themes in my research work (Box 1) and have structured this commentary in order to present each one in turn. Each theme relates to one or more publications submitted.

BOX 1: Key themes

- 1. Developing meaningful methods of patient and public involvement
- 2. How theory builds and develops
- 3. Reality of doing research in the real world

Patient and public involvement (PPI) and mental health issues are topics that have emerged and evolved during my research journey and appear in each of the themes above.

I have highlighted the key impacts and points of originality in inset boxes throughout the commentary, demonstrating how I have met the UWE doctoral descriptor. This is summarised in Appendix 2.

My submission of published papers is complemented by 23 unpublished research reports which I have listed in a bibliography (Appendix 3). I have also indicated the wider impact I have made and continue to make as a researcher (Appendix 4).

2. Publications submitted in support of the award

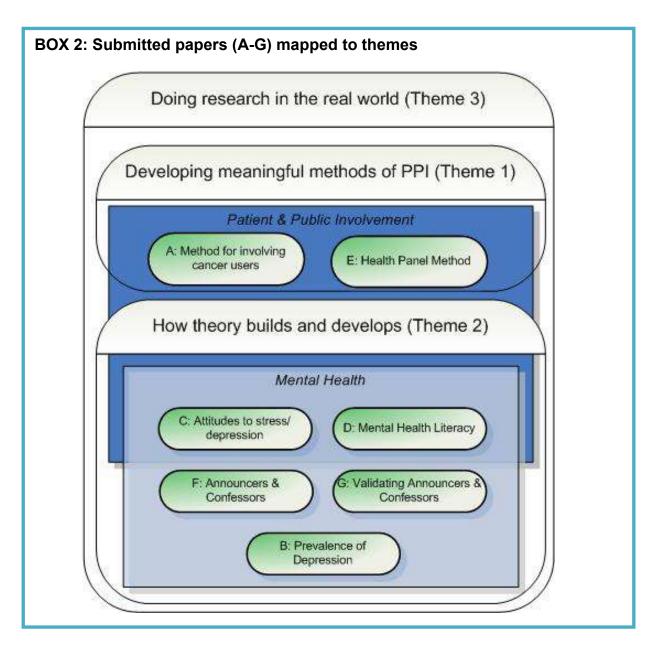
- a) Coe N, Purvis J, Barnes M. (2000) A method for involving users in the accreditation of cancer services. *Clinical Governance Bulletin*, 1(1), 4-6.
- b) Oliver MA, Pearson N, Coe N, Gunnell D. (2005) Help seeking behaviour in men and women with common mental health problems: cross-sectional study. *British Journal of Psychiatry*, 186, 297-301
- c) Coe, N. (2009a) Exploring attitudes of the general public to stress, depression and help seeking. *Journal of Public Mental Health*, 8(1), 21-31.
- d) Coe, N. L (2009b) Critical evaluation of the Mental Health Literacy conceptual framework using qualitative data. *International Journal of Mental Health Promotion*, 11(4), 34-44.
- e) Coe, N. L. (2012) Health Panels: The development of a meaningful method of public involvement. *Policy Studies*, *33*(3), 263-281
- f) Coe, N (2013a) Announcers and Confessors: How people self-disclose depression in health panels. *Health*, *5*(1), 79-88.
- g) Coe, N (2013b) Validating 'announcer' and confessor' styles of self-disclosure through use of archived qualitative data. *Health*, *5*(3A); 512-520.

Note: My papers are all published in my maiden name of Coe.

3. Commentary

<u>Introduction</u>

My published papers (Appendix 1) and unpublished work (Appendix 3) all contribute to the main themes (Box 1). Box 2 (below) summarises how my submitted papers contribute to these themes, and which topics they cover. It shows how the third theme (realities of doing research in the real world) underpins my research journey.



A topic that I have written most about is mental health, and, particularly in my published papers, on public attitudes to, and the disclosure of, depression.

Although I have covered other topics, mental health and PPI have been common

areas of focus throughout my research journey and in the themes I present in this commentary. Within the map in Box 2, I have also shown how these topics overlap in my papers, where I have focused on mental health, methods of PPI, or a combination of both. I return to these topics throughout my discussion of each theme below.

3.1 Theme 1: Developing meaningful methods of public involvement

I have used and developed innovative methods of PPI in the development of health services throughout my research career, as demonstrated by my published papers and through my portfolio of unpublished reports. These range from methods to involve children, adults, people with long term or life-threatening conditions, those who are dying and those that are yet to access any health services (see Appendix 3 for full list).

PPI can take many forms and purposes – to improve public understanding of science; to improve the design or delivery of research; to increase participation in research; to inform the development of services. The conceptualisation of PPI I have focused on in my research journey is that which has a purpose of developing services. As such it is the basis for the data collection for all my published papers and most of my unpublished reports. Therefore, this theme focuses on developing meaningful ways of collecting patient or public views in order that they have a voice in strategic decision making about health care services and treatments. For me, the terms 'patient' and 'public' in this context have some fluidity. Whilst some methods I have used (e.g. health panels) are presented as methods to obtain the 'public' views on a topic, it is the experiences of those 'public' as patients or users of services that are sought during the health panels – be it as

current, previous or potential users of services, both themselves or their friends and family. Other research I have undertaken has focused on a specifically defined 'patient' group e.g. palliative care patients, cancer patients, and expectant mothers (see Appendix 3).

I have demonstrated critical reflection on public involvement methods in all of my papers, and specifically in Coe, 2012 [Paper E]. In this paper, I expand on how formal methods of engaging with communities and ensuring that their views contribute to local health service planning in England have evolved. Methods of involving the patients and the public have been evident since the 1970s with the first major reform of the National Health Service (NHS) and with the establishment of community health councils (Secretary of State for Health and Social Services, 1972). The expectation to involve the public has continued through government policy since. The 1989 'Working for Patients' white paper (Department of Health, 1989) emphasised an expectation that health services in England needed to be increasingly responsive to the needs of their patient population. This was followed by the publication 'Local Voices' which challenged health authorities to develop effective methods of engaging with the public (NHS Management Executive, 1992). Then in 2001, the Health and Social Care Act placed a legal duty on organisations in England to involve and consult the public, while The National Health Service and Health Care Professions Act (2002) resulted in the establishment of a range of formal initiatives to redress this position. This included a PPI forum (PPIf) for each primary and secondary care NHS trust in England. However, PPIfs were severely criticised (House of Commons, 2007) and were soon replaced by Local Involvement Networks (LINks) (Health and Social Care Act, 2007) and subsequently by local HealthWatch (Department of Health, 2010).

The fundamental basis for all the policy changes described above is that PPI in health service planning, design and delivery is 'good', but unpacking what 'good', or 'meaningful' involvement means is the subject of complex debate. The duty to ensure PPI is viewed by some to restrict the scope of involvement to issues affecting user experience and choice and an overemphasis on bureaucratic central control (Hughes, Mullen & Vincent-Jones, 2009). The democratic deficit, the gap between those in control, at a government or local level and the public, has been widely discussed in the context of user involvement for many years (Hogg 2009; Cooper, Coote, Davies & Jackson, 1995). Embedded in this debate is a discussion over 'voice' versus 'choice' and the commitment to both has ebbed and flowed over the last 20-30 years under all three governments – Conservative, Labour and the current coalition. 'Choice' is a consumerist model, and seeks to drive improvements in services through the choice of different options, of using different services over others, whereas 'voice' is based on a citizenship model, positioning the public as influencers in the debates about how services should be configured. Despite a backdrop of UK policy concerned with strengthening 'voice', mainstreaming public involvement appears to have limited the ability for the public to actively participate in a creative process about their collective needs, and to ensure this has an impact on the development of those services. Hogg (2009) argues the increasingly devolved NHS might enable a more democracy-based opportunity for public involvement but clarity over whether this will be realised is yet to emerge.

One method of public involvement that I have spent a significant time working with and developing is health panels. Five of the papers I have submitted (written during my period of registration) and many of the unpublished reports, focus on the Somerset Health Panels' method and the data collected from it. These health

panels were established in 1994 as the main public involvement method to assist with difficult decision making and priority setting within the local health service in Somerset. In response to policy changes between 1994 and 2003, the Somerset Health Panels adapted and evolved at a pace that was acceptable within that policy context but also to the participants and the stakeholders involved. The changes (summarised later in this section) demonstrate a shift from 'choice' to 'voice' and the method described enables a democracy based model to emerge.

The Somerset Health Panels ran two to three times ('rounds') per year until 2003. I was the lead researcher for them from September 2000 to April 2003, having been involved with them as a collaborator since April 1999. Many of my unpublished reports (Appendix 3) are from this period. I retained access to the original transcripts for eight rounds of Somerset Health Panels (i.e. 96 transcripts in total). During my involvement with thesepanels, I influenced their design, undertook the analysis, wrote reports to summarise the discussions and supervised other members of my department to do the same.

The Somerset Health Panels have become extensively referenced in over 100 peer-reviewed publications (see Coe, 2012 [Paper E]), in various Department of Health reports, reviews and in guidance and toolkits on PPI (Department of Health, 2003b). However, aside from two very early papers describing the original design (Bowie, Richardson, & Sykes, 1995; Richardson, 1997), no other peer-reviewed papers have been written about the Somerset Health Panels design or reported on the data produced by them. This provided me with a unique opportunity - not only to update the literature and examine the data more fully, but also to fulfil a personal sense of completion about the contribution I had made as a researcher during this period.

In my paper on the Somerset Health Panels method (Coe, 2012 [Paper E]) I take the opportunity to update the two previous papers and explore the changes to the health panels design. These changes included the management and organisation of the health panels; the impact of NHS reconfiguration; and changes and relationships within the research team (See Box 3 for summary of key insights from this paper). The Somerset Health Panels were commended for their sustainability (Institute of Public Policy Research/Guardian Award for Patient and Public Involvement, 2001) and are held up as an exemplar model of public involvement. The unique insider perspective I have on how the panels developed over a decade, allowed me to demonstrate not only originality but also a critical understanding of the research method itself. Within the paper, I reflect on the relative strengths and weaknesses of health panels in comparison to other methods such as citizen juries and government led public involvement structures e.g. PPIFs and LINks. Writing this paper also enabled me to position my other publications and provides the necessary background and up-to-date description of the health panel method. I wrote the first draft of this paper (Coe, 2012 [Paper E]) early in my period of registration and intellectual journey, with the intention of then being able to make reference to it in my other papers. However, due to the vagaries of the peer review system, it was actually published later than other papers that it influenced. I expand on this issue in section 3.3.

Within the paper on the Somerset Health Panels method (Coe, 2012 [paper E]) I explain the basic health panels design - each 'round' of panels comprised of a series of 12 groups, each lasting two hours, spread across the county of Somerset and facilitated by an independent facilitator. Each group comprised 10-12 members of the public who discussed between one and three health related

questions which were relevant to the local health organisations (e.g. the health authority, the community health council and latterly the acute, mental health or primary care trusts (PCTs)). I also demonstrated the changes to the design and what brought about those changes. For example, up until 1999, the Somerset Health Panels aimed to achieve consensus and participants were asked to complete 'decision sheets' at the end of the discussion to answer specific questions posed (e.g. "Should Somerset Health Authority limit the availability of breast reduction surgery?") and it was the analysis of the decision that was considered most relevant by the stakeholders, not the detailed discussions.

However, the increased recognition of qualitative research by the stakeholders, the increasing PPI agenda in the NHS, along with changes in the research team, meant that decision sheets were removed in 1999 and subsequent reports comprised of a thematic analysis only. In reflecting on the reasons why the Somerset Health Panels methodology changed I was able to demonstrate in the paper that having relevant topics, confidence in the design, methodological validity (perceived and actual) and results that will demonstrate an impact, are all key to ensuring involvement of patients or the public is meaningful. I also concluded that whilst these factors are important for each group (the stakeholders, the researchers and the participants), there are subtle differences in how these factors are interpreted, and that this interpretation can flex and change over time. As such local sensitive methods create a more meaningful method of public involvement. During the period that the Somerset Health Panels were active, a considerable amount changed externally – on the political landscape, in the culture of health services research, in the acceptance of qualitative research methodology and in how and why the public's views were heard.

BOX 3: Key insights from Paper E: Coe, N. (2012) Health Panels: The development of a meaningful method of public involvement. *Policy Studies*, 33(3), 263-281:

- The Somerset Health Panels is an example of how healthcare organisations
 can fulfil their legal duty and a moral obligation to find appropriate,
 sustainable, sensitive, flexible and cost effective methods by which to engage
 with patients and the public
- The paper describes a methodology at the forefront of its field at the time
- It provides an analysis of the changes that took place during the development of the panels from 1994 to 2003
- Only topics that could influence service development were discussed by the Somerset Health Panels
- A response was required from stakeholders as to how the views of the panels had influenced developments
- Funding was committed by all the organisations involved
- Dedicated staff provided support and training to both participants and those receiving the results
- As the public involvement agenda continues to strengthen in England under the coalition government, lessons learnt about the sustainability, adaptability and flexibility of the panels are as important today as they were then

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 3) Conceptualise, design and implement a project
- 4) Critical understanding of the methodology of enquiry
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

Although the Somerset Health Panels were a geographically limited and now historical project, sensitive and local methods of PPI in service development continue to be required: The PCTs had limited confidence in LINks or PPIfs (Chisholm et al, 2007) and there has already been concerns expressed that the new local HealthWatch will lack sufficient funds to operate effectively and ensure patient views are heard by providers (The King's Fund, 2012). As a local initiative, health panels can have a broader and more flexible design than models imposed nationally, such as LINKs, PPIfs and HealthWatch, while continuing to share a similar purpose to other methods i.e. to seek the views of the local community. As a result other local methods of accessing the views of the patients and the public will become increasingly important as the current government develop policy in this area – and therefore the relevance of the lessons learnt from the Somerset Health Panels remains significant.

As acknowledged for many other examples of PPI, and particularly in its relation to strategic decision making, I recognise in the paper that impact, or added value, is hard to determine. However, in contrast to other papers (for example those referred to in the systematic review by Mockford, Staniszewska, Griffiths, Herron-Marx, 2011) the costs of the initiative and at least the feedback from stakeholders and sponsors was included.

In my earlier paper (Coe, Purvis & Barnes, 2000 [Paper A]), I present an innovative method used to involve current or previous cancer patients in the accreditation of cancer services (see Box 4 for key insights from this paper). The involvement of patients in this context is relevant to both the 'choice' and 'voice' agenda as although the accreditation process is focused on the 'choice' agenda, the importance of the 'voice' of the patient in that process has been nationally

recognised. The paper provides additional considerations that were made in terms of recruitment and conducting focus groups and interviews that were sensitive to the needs of those involved. For example, the recruitment of participants was guite different to that used for the Somerset Health Panels where participants were recruited door-to-door, whereas for the accreditation of cancer services, participants were identified from a regional cancer registry. Only those that had received a diagnosis of cancer within the previous two years were initially invited to participate. Extra ethical precautions were taken to ensure it was acceptable to contact each person; their GP checked individuals who were to be invited were not too ill to be contacted and invitation letters were sent from the GP. I was mindful in this research of establishing and discussing the boundary between focus groups for research and group therapy. This was challenging because, despite being aware of the need for clarity on this issue, participants frequently reported that the experience had been therapeutic for them i.e. to discuss their condition and care pathway with others going through the same treatments or with the same cancer This was also something reported by participants in the Somerset Health Panels on occasion.

The Somerset Health Panels and the involvement of patients in the accreditation of cancer services are two examples of ways I have developed meaningful, innovative and effective methods of involving the public. The Somerset Health Panels, in particular, form a substantial part of the theme of public involvement research within my doctoral journey as illustrated in Box 2.

BOX 4: Key insights from Paper A: Coe N, Purvis J, Barnes M. (2000) A method for involving users in the accreditation of cancer services. *Clinical Governance Bulletin*. 1(1), 4-6

- The use of separate focus groups specific to different tumour sites is an effective way of eliciting users' views of services
- Users' views can be successfully incorporated as part of the accreditation of services
- It is important to gain the support of doctors and managers in primary care so they support the patient and the researcher
- Maintaining flexibility over the groups meant that they were accessible to most people

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 3) Conceptualise, design and implement a project

3.2 Theme 2: How theory grows and develops

Four of my submitted papers [Papers C, D, F, G] feature qualitative data from one specific Somerset Health Panels round where the groups discussed attitudes and barriers to seeking help for depression and stress related disorders. For these papers, I have reanalysed these data, collected originally during the Somerset Health Panels to inform service developments.

The four papers are linked to my earlier quantitative paper on help-seeking behaviour for depression and stress (Oliver, Pearson, Coe & Gunnell, 2005 [Paper

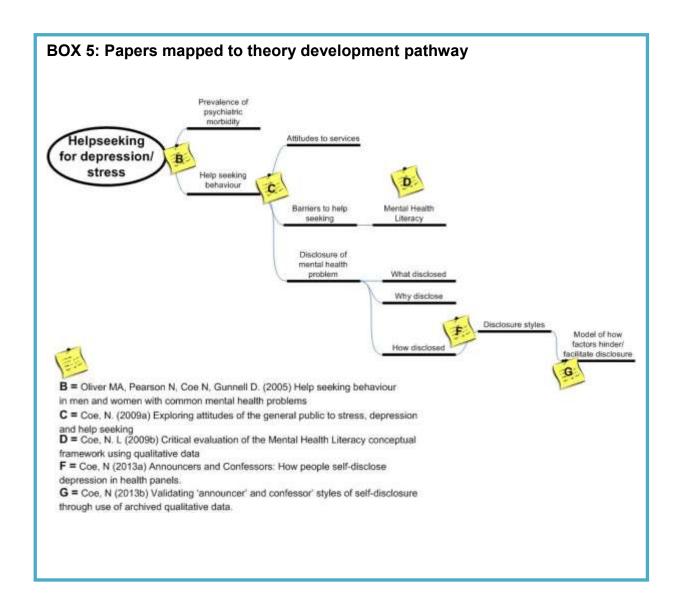
B]) and, of all the topics discussed by the Somerset Health Panels, the subject I was most interested in.

These five papers, forming a major part of my submission, are written in a sequence that reveals two pathways of theory development:

- Pathway one relates to my contribution to the literature concerning help seeking behaviour of people with stress and depression
- Pathway two relates to the development of a model to understand the way in which people communicate and self-disclose information about themselves

These pathways, one (revealed by papers B-C-D) and two (by papers B-C-F-G), are illustrated in Box 5. I will now describe how each paper delivered a part of the theory development and how each evolved into the next.

A key feature of my submission is that, for each pathway, I initially analysed the data using an inductive thematic analysis approach (Braun & Clarke, 2006), and then for the final paper in each pathway (Coe, 2009b [Paper D]; Coe, 2013b [Paper G]) I moved to a deductive framework analysis approach (Ritchie & Spencer,1994). This enabled me to validate what emerged at the inductive stage with other frameworks (pathway one) or with other data (pathway two).



3.2.1 Development of pathway one – attitudes to depression and help-seeking

As previously noted, there have been over 100 citations of the Somerset Health Panels methodology but no results have previously been published. My paper on the attitudes of the general public towards stress and depression (Coe, 2009 [Paper C]) was therefore the first primary results paper utilising the Somerset Health Panels' data. It generates new knowledge on the way in which people want to access services, filling a gap in the current literature. It also validates the use of health panels as a method for public involvement and demonstrates my critical understanding of the current literature in this field.

The topic for the Somerset Health Panels' discussion was identified as a direct result of a large-scale population survey to determine the population prevalence of neurotic psychopathology (for which I was also a researcher). The results of this are described in my earlier paper (Oliver, Pearson, Coe & Gunnell, 2005 [Paper B] and the subsequent Somerset Health Panels' discussion further explored the public attitudes about depression and stress related disorders, sources of support and help-seeking.

The prevalence of mental health problems is extremely high – as many as one in three people will be experiencing a mental health problem at a given time (Oliver, Pearson, Coe & Gunnell, 2005– see Box 6 for key insights from this paper) and the lifetime likelihood is up to 50% (Kessler et al, 1994). Therefore, it is probable that at some stage in our life we will all either develop a mental health problem ourselves or know someone close who has. However, many people do not seek professional help and those that do often delay seeking help for a number of years (Barney, Griffiths, Jorm, & Christensen, 2006; Christiana et al, 2000).

BOX 6: Key insights from Paper B: Oliver MA, Pearson N, Coe N, Gunnell D. (2005) Help seeking behaviour in men and women with common mental health problems: cross-sectional study. *British Journal of Psychiatry*. 186, 297-301.

- One in three people were found to have a common mental health problem (scored 4+ on the GHQ-12)
- Of those with the highest scores (>7 on GHQ12), only 25% had sought help from their general practitioner, although most (78%) had sought some form of help from friends or family.
- Men, young people, and people living in affluent areas were the least likely to seep help.

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 3) Conceptualise, design and implement a project
- 4) Critical understanding of the methodology of enquiry
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

Understanding help-seeking behaviour enables us to consider the suitability and acceptability of support available to people with mental health problems, the barriers they feel in accessing that support and, more broadly, the psychological processes that underpin help-seeking behaviour. Previous research has suggested the barriers to seeking professional help relate either to perceptions about the 'help-giver' (such as feeling that the GP doesn't have time, there is nothing the GP can do or it will be seen as trivial) (Cape & McCulloch, 1999; Kadam, Croft, McLeod, & Hutchinson, 2001); or about the way in which the help-seeking would be perceived by other people (e.g. that others would think less of us if we went to see a psychiatrist or psychologist) (Angermeyer, Matschinger & Riedel-Heller, 1999). There is also considerable evidence from both clinical and lay populations of the importance of the social network in providing support.

Therefore, the experiences and attitudes of our friends and family and our wider social network are likely to be critical in influencing how we seek help (Angermeyer, Matschinger & Riedel-Heller, 1999, 2001; Cooper-Patrick et al, 1997; Dew, Dunn, Bromet & Schulberg, 1998; Rickwood & Braithwaite, 1994; Roness, Mykletun & Dahl, 2005; Komiti, Judd, & Jackson, 2006; Vogel, Wade, Wester, Larson & Hackler, 2007). Given the importance of the social network, establishing the wider public's views is essential. This, combined with a lack of any published qualitative research, provided me with two very tangible and relevant reasons to make a meaningful contribution to the literature. The key insights from this paper are highlighted in Box 7. The progression from a quantitative paper to two papers reporting qualitative data is an example of what other researchers have termed a mixed methods approach in real world research (Dures, Rumsey, Morris & Gleeson, 2010). I explore this real world context in more detail in section 3.3.

During the Somerset Health Panels discussions on attitudes to depression and help seeking an unanticipated but interesting observation arose. The discussion was intended to provide a 'public' perspective on this subject, and yet a significant proportion of the participants turned out to have had personal experience of coping with a mental health problem. During the original analysis I noticed that in each group, at least one participant (and in most groups more than one) disclosed they had experienced a mental health problem (which they self-defined) - in total 27 (28%) participants (18 women and 9 men). Although this was noted in the original report from the panel, it was not explored in any detail. However, on reflection, it further illustrated the dynamic definition of the 'patient' and 'public' and presented an area for further exploration which is discussed later in this section.

During the process of writing this paper a number of issues led me to re-evaluate the overall aims of my doctoral programme and subsequently revise my publication plan to maintain a focus on depression and help-seeking. Firstly, during my literature review for this paper, I discovered that although a great deal had been written about attitudes to mental health from a patient perspective and there have been a number of national population surveys (Department of Health, 2003a), very little had been published about attitudes of the public using qualitative methods. This presented a significant gap in the literature that I was able to fill. During the literature review for the primary results paper, I identified a theoretical model of 'Mental Health Literacy' (Jorm, 2000). This model is not explicitly dataderived and, although it is referenced in many other papers, there appears to be limited testing against any primary data, presenting an opportunity for me to make a further original contribution to the literature. So, in my subsequent paper, I then critically evaluated Jorm's Mental Health Literacy framework (Coe, 2009 [Paper D]) using the primary data from the same Somerset Health Panels' discussion of attitudes to stress and depression.

BOX 7: Key insights from Paper C: Coe, N. (2009a) Exploring attitudes of the general public to stress, depression and help seeking. *Journal of Public Mental Health*. 8 (1), 21-31

- There are significant similarities between the attitudes of a lay population compared to previous research with users of mental health services.
- The results support previous user research findings about the attitudes and perceptions of help-givers, such as the GP, the psychiatrist and counsellor, and reinforce how critical the role of friends and family are in supporting people who suffer from stress and depression.
- Attitudes within the groups between those who disclosed a mental health problem during the course of the discussion and those that didn't were extremely similar
- In contrast to previous quantitative studies of the 'general public', participants in this research personally held a very non-judgemental and sympathetic attitude to others with stress and depression.
- I identified and presented a new hierarchy of preferred sources of help, where as the perceived severity of the mental health problem increased, the acceptability (to the person themselves and to others) of seeking help from the specific source also increased.
- This hierarchy also reflected the increasing levels of stigma associated with the different types of help available.
- The preferences of help-seeking do not match the current way in which services are provided – for example, there was a strong preference by the panels that following seeking help from a GP, support from self-help groups was their preferred next step.

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

Jorm considers there are six specific themes that contribute to the public's mental health literacy:

- The ability to recognize specific symptoms/disorders
- Knowledge and beliefs about risk factors and causes
- Knowledge and beliefs about self-help interventions
- Knowledge and beliefs about professional help available
- Attitudes which facilitate recognition and appropriate help-seeking
- Knowledge of how to seek mental health information

I re-analysed the health panels' data using a framework analysis approach, regrouping original coding into the six themes within Jorm's model. My critical evaluation of the model demonstrated that the Mental Health Literacy framework provides an appropriate architecture for the range of research and discussion on this topic, although qualitative research adds depth to what was known previously. In addition, I had generated new insights that indicate how the model might be adapted or expanded in the future. A summary of the contribution made by the analysis of the health panels' data added to what is already known about mental health literacy is provided in Box 8, demonstrating how the paper contributes to the development of theory and to the literature (see Box 9 for wider key insights from this paper).

BOX 8: Summary of what analysis of the Health Panels data contributed to what was already known about mental health literacy

Mental Health Literacy Framework component	What is already known	Key findings from Health Panels
The ability to recognize specific disorders or different types of psychological distress	 72% able to identify a mental health problem from vignette description of symptoms 39%/67% recognised description as depression (2000/2006) rising to 67% Poor recognition and knowledge about the symptoms of mental health problems will result in problems communicating with others 	 There is difference between knowledge and recognition of depression in hindsight and the ability to recognise symptoms as they are developing Supports previous research of good awareness of a wide range of symptoms
Knowledge and beliefs about risk factors and causes	 Main causes perceived to be day-to-day problems, traumatic events, recent death, and childhood events, unemployment or a relationship breakdown 	 Accumulated adversity seen as key Work and financial issues were the main themes seen as lack of opportunity to effect change on personal circumstances Social issues are perceived as important including isolation, boredom Biological and genetic factors are not well known as social/ environmental factors
Knowledge and beliefs about self-help interventions	 Strong preference for seeking help from family and friends, engaging in enjoyable and new activities, and exercise Help-givers have concerns about their skills in dealing with others with mental health problems 	 Self help considered same as 'coping' Self help, and specifically seeking help from friends/family seen as key step in seeking professional help Limited concern about lack of skills to provide support to others Support previous research on preferences for types of self-help
Knowledge and beliefs about professional help available	 General practitioner rated highly Negative perception of medication 	General Practitioner seen as the gatekeeper to other professional help Support groups viewed very positively Supports previous research on overall positive/negative attitudes to GPs, medication, counselling, psychiatry
Attitudes which facilitate recognition and appropriate help-seeking	Stigma hinders help-seeking	Stigma is evident but is not perceived to always prevent help-seeking Attitudes of other people they knew, of 'society' and of the media perceived to influence behaviour General Practitioner acts to counter perceived stigma Support groups may act as a bridge between self-help and professional help
Knowledge of how to seek mental health information	 Main sources are perceived to be personal experience and the media The media may present a negative and biased representation of mental illness 	 Established health promotion methods – leaflets, posters, newspaper adverts and TV Raising awareness should start at school

BOX 9: Key insights from Paper D: Coe, N. L (2009b) Critical evaluation of the Mental Health Literacy conceptual framework using qualitative data. *International Journal of Mental Health Promotion*. 11 (4), 34-44.

- There are increased challenges about recognising symptoms as they emerge,
 compared with 'with hindsight'
- There is a subtle balance between stigma and barriers to help seeking
- Accumulated adversity is perceived to be a key risk factor
- Coping strategies and stigma are cross-cutting themes
- The general practitioner has significant influence in facilitating access to appropriate support.

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 3) Conceptualise, design and implement a project
- 4) Critical understanding of the methodology of enquiry
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

3.2.2 Development of pathway two – process of disclosure

Reflecting on the development of both papers C and D on public attitudes to depression, I noticed that the openness, honesty and challenging nature of discussions did not indicate opinions were being reserved. This reflection led me to consider exploring a separate but related pathway of theory development; the process of how disclosures were made by some participants and how these disclosures might have been affected by others in the group. This is a key stage in my personal research journey, again linking the topics of mental health and PPI together through the consideration of wider methodological issues.

I reviewed the literature on disclosure and found that although much is written on what people disclose, it is acknowledged that few papers include the context and interaction between participants to demonstrate 'why' and 'how' they thought (Kitzinger, 1994). I therefore decided to specifically analyse 'how' people disclosed depression. Through the analysis of the Somerset Health Panels data I conceptualised two main styles by which people made disclosures, which I named 'announcers' and 'confessors' (Coe 2013a [Paper F]). The characteristics of the two styles emerged in the coding and themes that were derived from them but the clustering of those codes into the two styles was an insightful idea that I then retested against the data to confirm that as categories they were robust. Key insights from this paper are highlighted in Box 10.

As the concept of two styles of disclosure had been derived from one dataset, I felt it important to validate this emergent theory using other data. In my earlier papers I had reanalysed my own data but the reuse or secondary analysis of other people's qualitative data has also been made accessible to researchers through the establishment of the Economic and Social Data Service (ESDS) Qualidata as part of the UK data archive. One of the datasets available was from "The Cultural Context of Youth Suicide: Identity, Gender and Sexuality" study (Roen, Scourfield, & McDermott, 2008) and I selected this for comparison to the data from the Somerset Health Panels as it was a

BOX 10: Key insights from Paper F: Coe, N (2013a) Announcers and Confessors: How people self-disclose depression in health panels. *Health*, 5(1), 79-88.

- Two main styles by which people disclose personal stories were conceptualized in this article – 'announcers' and 'confessors'
- The concept of two styles will be of significance to those who work with group-based research methods and/or with people with stigmatized health conditions including mental illness and depression in particular.
- Key factors that help or hinder disclosure were also identified the use of normalizing comments (by disclosers, other participants and the facilitator); the impact of setting the tone; the impact of others responses to disclosures and partial disclosures.
- Health panels can be used as an effective method to discuss sensitive topics.

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 3) Conceptualise, design and implement a project
- 4) Critical understanding of the methodology of enquiry
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

similar discussion topic, the data had been collected from other parts of the UK, and it involved different age groups. My analysis of the youth suicide data enabled me to validate the concepts from the previous paper (Coe, 2013b [Paper F]) again using a framework analysis approach. The insights from this paper are summarised in Box 11. In concluding this paper, I include an emergent model that I have developed which demonstrates how a variety of factors hinder or facilitate disclosure – a new contribution to the literature on this topic.

BOX 11: Key insights from Paper G: Coe, N (2013b) Validating 'announcer' and confessor' styles of self-disclosure through use of archived qualitative data, *Health*, *5*(3A); 512-520.

- The concept of two styles of self-disclosure, announcers and confessors, was validated.
- The concept is refined into an emergent model for how a variety of factors (risks and contexts) not only hinder or facilitate disclosure but also how they impact on the style by which people disclose
- Important considerations for researchers are identified when designing focus group based research in how to facilitate self-disclosure.
- Qualitative data can be reused successfully and the value of accessible and appropriately archived qualitative data on theory building and the development of models of communication and social interaction is demonstrated.

Evidence of doctoral descriptor:

- 1) Creation and interpretation of new knowledge
- 2) Critical understanding of the current state of knowledge
- 3) Conceptualise, design and implement a project
- 4) Critical understanding of the methodology of enquiry
- 5) Judgement of issues and ideas
- 6) Critically reflect and evaluate strengths and weaknesses

3.3 Theme 3: The challenges and opportunities of doing research in the real world

The Somerset Health Panels along with my other unpublished reports were all originally designed with health service development-based questions in mind; their concept and design was embedded in the need to evaluate the effectiveness of specific service developments or to plan and improve how services may be delivered to a population. Timescales were often dictated by planning or other deadlines and funding for the research was limited. As a consequence, the design, analysis and reporting had to be adapted to take these factors into account. For example, the primary aim of each Somerset Health Panels round was to produce a summative report for those designing services and therefore this dictated the depth of information collected about the participants. So, while the results are of relevance to a wider audience, and therefore warrant publication, the primary audience for the original Somerset Health Panels reports were the managers responsible for planning that health service. Therefore, what might have been designed in a purist academic environment was not practical when undertaking health services research in the 'messy reality' of health service practice. 'messy reality' is acknowledged by other researchers (Mellor, 2001; Minkin, 1997; Fine & Deegan, 1996). Mellor (2001) provides a detailed personal account of where his messy reality buffers against 'validity' and 'science', which resonates with my own experience. This reality presented a challenge to me specifically when trying to publish papers during my registration period. For example, in my attempts to publish the paper focusing on the health panels method (Coe. 2012) [Paper E]), I received numerous reviewer comments that I had failed to collect relevant demographic data on participants; that I had failed to include an evaluation of the impact of the health panels reports, and that I had failed to explain adequately why the method had changed over time. The 'messy reality' was that for the purposes of the original aims there had been no need for detailed demographic information on participants as no-one was interested! Furthermore, at the time, anecdotal feedback that participants valued their involvement in the Somerset Health Panels, and that the sponsors of the panels and other organisations found the reports useful, was sufficient justification of their value rather than a detailed, planned evaluation of impact. Whether this is right or wrong in a purist research sense is not the question, it is what happened, and in that regard, it is the reality experienced by me as a pragmatic researcher - like many other health service researchers.

The 'messy reality' became more of a challenge in writing the papers that contributed to theory development (Coe, 2013a,b [Papers F, G). Initially, I fell into a trap of trying to shoehorn what had happened in reality into the formula expected from journals, and tried to retrospectively justify why the data had been collected in the way that it had. Reviewers' comments helped me to acknowledge a more honest reality of the data collection and to make this explicit in my writing (Coe, 2013a [Paper F]). The final paper was within the context of an applied research method, the health panel, which I acknowledge in the paper was designed with the main aim of capturing what people thought about the topic so that it could shape local health services. I have demonstrated through this paper that it is possible to look at interactions between participants even though this was not originally the main research goal. I also responded to the limitations of building theory from one data set collected for a different purpose, by using secondary analysis to validate and build that theory as it started to emerge (Coe, 2013b [Paper G]).

My 'messy reality' also extends to the doctoral process. A small number of papers discuss the doctorate by publication and tend to focus on quality assurance issues (Hoddell, Street & Wildblood, 2002; Bradley, 2009). Other authors reflect on the practical challenges experienced. When I reflect back on my experience of the doctoral process, I can make a number of similar observations but will focus on two in this narrative – the impact on my intellectual journey, and the challenge presented by the publishing process.

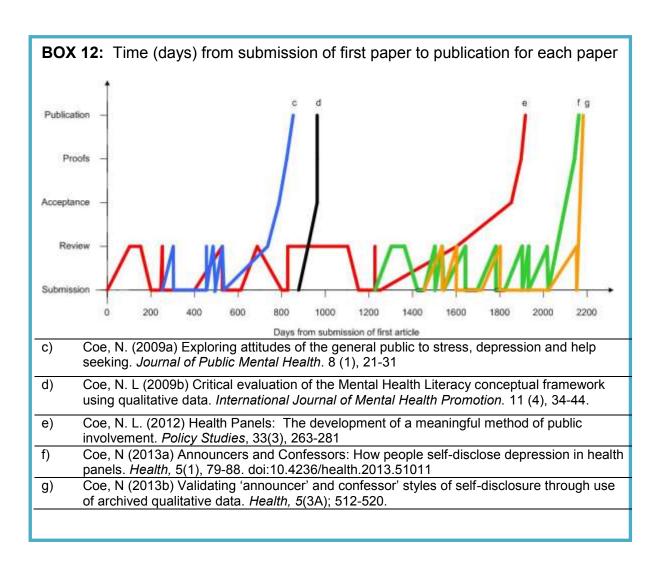
Firstly, I have developed and deepened my thinking as a researcher and taken on board reviewer comments and challenges, and as such the quality of my writing has no doubt improved over my registration period. Although first drafts of early papers may have been significantly less robust than the equivalent for later ones, the delays in publishing papers the papers which I drafted early in my registration period afforded me the option to revise them over a period of some years before final publication. For me, part of my doctoral journey has been the learning I have gained via the peer review process and how I've responded to feedback – the peer review process itself adding to the intellectual challenge and value of doing a doctorate by publication route.

Secondly, as an experienced project manager and researcher, the unpredictability of timelines in this doctoral route presented a personal challenge during my registration period. Publishing academic work is a stressful process even in the most favourable conditions, and experienced academics and novice researchers both identify the challenges and problems encountered in the publication journey (Birchenall, 1997). In particular, journal lag times have been identified as possible stumbling blocks in the doctorate by publication (Robins & Kanowski, 2008). Mapping the timelines for each of my papers from submission to publication (Box

12) shows how I wrote some papers in parallel. It is particularly evident that there was a significant delay in securing publication of what I originally intended to be the first paper published (Coe, 2012 [paper E]). Although frustrating, this presented an opportunity as I could revise and improve the draft manuscript many times alongside my intellectual journey.

The time between first submission and final publication ranged between 88 days to 1925 days (mean 843 days; median 701 days); twice as long as that reported elsewhere (Robins & Kanowski, 2008). This created a challenge in undertaking a doctorate by prospective publications in terms of some loss of control over timescales. Some of the time delay between first submission and publication is time spent revising manuscripts (shown as horizontal lines), but the longest delays were waiting for reviewer comments, particularly for paper E.

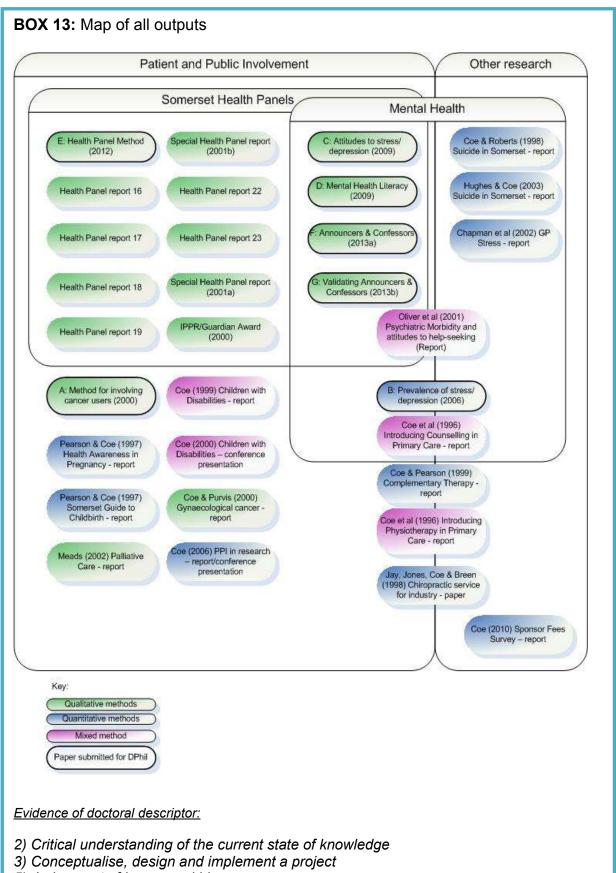
Another challenge related to timescales I experienced was when writing sequential papers towards the end of my registration period (i.e. papers F & G). Acknowledging that a journal would wish a preceding paper to be accepted for publication ahead of reviewing the subsequent one, this impacted upon my timescale for papers F and G in particular. Although I had written paper G I had not secured publication of paper F. As a result I purposefully held back paper G until paper F had been accepted (eight months), although as paper G was then reviewed and accepted very quickly after submission this did not substantially increase my overall timeline.



3.4 Wider outputs

I have a significant number of unpublished but publicly available reports that fit coherently with my two main topic areas of interest, in that they either relate to mental health or PPI. They include a number of Somerset Health Panels reports (8 reports) and other research reports I have produced (15 reports). Most were produced for a specific NHS organisation or group of organisations, although a few later reports have been published nationally as guidance. A map of all my publications (peer-reviewed publications and other reports) is provided in Box 13. I provide full details of these in Appendix 3.

These wider outputs again demonstrate two overlapping topics - PPI (and specifically the Somerset Health Panels) and mental health (Box 2). I have outlined in bold the papers submitted and also indicated whether qualitative (green), quantitative (blue) or mixed methods (purple) have been used to aid interpretation and show my breadth of research. Whilst the unpublished reports may not contribute to doctoral descriptor element 1 (in that they were not subject to rigorous peer-review) they do contribute to demonstrating my achievement of other doctoral descriptor elements as listed.



5) Judgement of issues and ideas

4. Conclusion

I have made an original contribution to a number of areas of the literature:

- a) Developing meaningful methods of involving the public in health services development and accreditation
- b) Understanding the attitudes of the public to stress, depression and helpseeking
- c) Understanding how people self-disclosure to others.

I have demonstrated the richness of health panels' data, culminating in:

- The development of a new emergent model of disclosure
- Further development of a theoretical model of mental health literacy.

My papers have been cited over 100 times by others since publication (see Appendix 1 for examples) and my work is recognised in national guidance (Department of Health, 2003). I have been invited to join numerous national working groups, advisory committees, debates, reference groups and policy advisory breakfasts with government concerning PPI and also the methods and processes of research (see Appendix 4). Combined with my extensive collection of reports and wider research outputs (Appendix 3), these esteem factors demonstrate the contribution and the impact I continue to make as a researcher; in interconnected areas of mental health, PPI and wider research methods.

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Appendix 1: Portfolio of Papers submitted in support of the award

a) Coe N, Purvis J, Barnes M. (2000) A method for involving users in the accreditation of cancer services. *Clinical Governance Bulletin*. 1(1), 4-6.

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Hubbard, G., Kidd, L., Donaghy, E., McDonald, C., Kearney, N. (2007) A review of literature about involving people affected by cancer in research, policy and planning and practice. *Patient Education and Counselling*. 65(1); 21-33

Rees G. (2003) Lay influence on service provision: impact of a Royal College Patient Liaison Group on radiotherapy departments *Journal of Radiotherapy in Practice*. 3: 85-90

b) Oliver MA, Pearson N, Coe N, Gunnell D. (2005) Help seeking behaviour in men and women with common mental health problems: A cross-sectional study. *British Journal of Psychiatry*. 186, 297-301.

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Also: Oliver I, Coe N, Pearson, J, Bellamy J (2001). Study of the prevalence of psychiatric morbidity and help-seeking behaviour for psychiatric symptoms among adults in Somerset. Somerset Health Authority Report

c) Coe, N. (2009) Exploring attitudes of the general public to stress, depression and help seeking. *Journal of Public Mental Health*. 8 (1), 21-31

Cited by 1 paper:

Irvine, A. (2011) Something to declare? The disclosure of common mental health problems at work. *Disability & Society*. 26 (2), 179-192

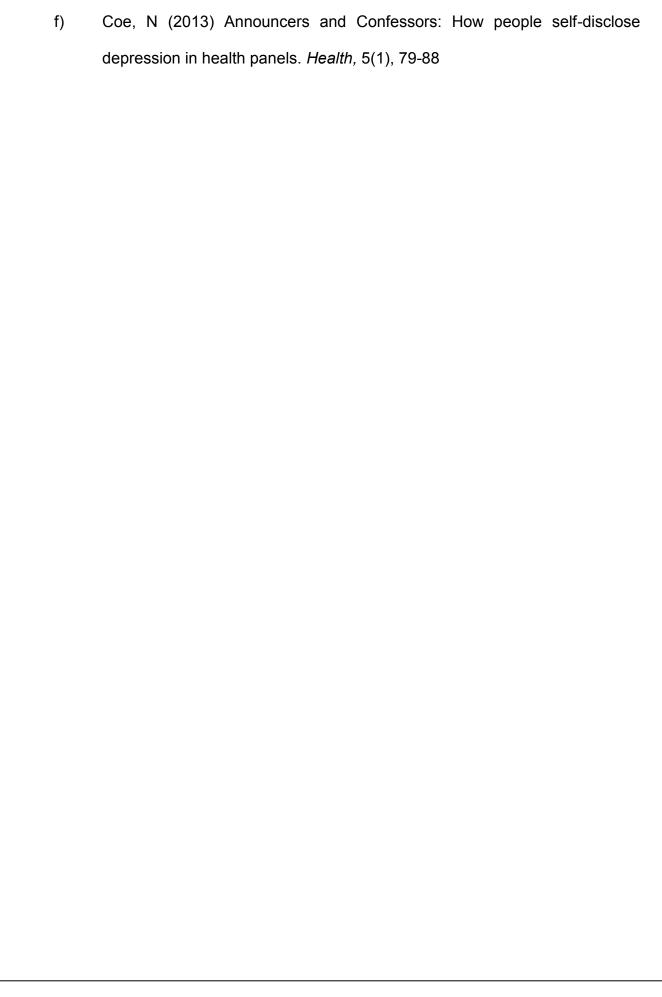
d) Coe, N. L (2009) Critical evaluation of the Mental Health Literacy conceptual framework using qualitative data. *International Journal of Mental Health Promotion*. 11 (4), 34-44.

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Appendix 2: Map of evidence against UWE doctoral descriptor

Paper		Doct	Doctoral descriptor			
· sp s.	1	2	3	4	5	6
Oliver MA, Pearson N, Coe N, Gunnell D. (2005) Help seeking behaviour in men and women with common mental health problems: crosssectional study. <i>British Journal of Psychiatry</i> . 186, 297-301	Х	Х	х	Х	X	Х
Coe N, Purvis J, Barnes M. (2000) A method for involving users in the accreditation of cancer services. <i>Clinical Governance Bulletin.</i> 1(1), 4-6	Х		(X)			
Coe, N. (2009) Exploring attitudes of the general public to stress, depression and help seeking. Journal of Public Mental Health. 8 (1), 21-31	Х	Х	(X)	(X)	Х	х
Coe, N. L (2009) Critical evaluation of the Mental Health Literacy conceptual framework using qualitative data. <i>International Journal of Mental Health Promotion</i> . 11 (4), 34-44.	Х	Х	(X)	Х	Х	х
Coe, N. (2012) Health Panels: The development of a meaningful method of public involvement. <i>Policy Studies</i> , 33(3), 263-281	Х	Х	(X)	Х	Х	Х
Coe, N (2013a) Announcers and Confessors: How people self-disclose depression in health panels. <i>Health</i> , 5(1), 79-88.	Х	Х	Х	Х	Х	Х
Coe, N (2013b) Validating 'announcer' and confessor' styles of self-disclosure through use of archived qualitative data. <i>Health</i> , <i>5</i> (3A); 512-520.	X	Х	Х	Х	Х	Х
Narrative	Х	х	х	Х	X	Х

(x) = Partially met

Doctoral Descriptor

- Conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field
- 2. Demonstrated a critical understanding of the current state of knowledge in that field of theory and/or practice
- 3. Demonstrated an ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice, including the capacity to adjust the project design in the light of emergent issues and understandings
- 4. Demonstrated a critical understanding of the methodology of enquiry
- 5. Developed independent judgement of issues and ideas in the field of research and/or practice and is able to communicate and justify that judgement to appropriate audiences
- 6. Can critically reflect on his/her work and evaluate its strengths and weaknesses, including understanding validation procedures.

Appendix 3: Bibliography of other work

This appendix provides a bibliography of other work I have authored and supplements the published work submitted for this award.

Other peer-reviewed published papers

Jay, T. C., Jones, S. L., Coe, N., and Breen, A. C. (1998) A chiropractic service arrangement for musculoskeletal complaints in industry: A pilot study.

Occupational Medicine, 48(6), 389-395.

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Methods. *Journal of Whiplash & Related Disorders*, *5*(1), 15-24.

Reports from Somerset Health Panels

Coe N, Purvis J (1999) Report of the sixteenth round of panels held in April-May 1999. Somerset Health Panels Report, Somerset Health Authority.

 this report covers the following topics: Complementary therapy within the NHS; The development of NHS Direct; Confidential drug services for young people; The role of Taunton Community Hospital.

Coe N, Purvis J (1999) Report of the seventeenth round of panels held in September-October 1999. Somerset Health Panels Report, Somerset Health Authority.

this report covers the following topics: Coronary heart disease;
 Teenage conception; Accidents in children under four years old.

Coe N, Purvis J (2000) Report of the eighteenth round of panels held in April-May 2000. Somerset Health Panels Report, Somerset Health Authority.

this report covers the following topics: Access to GP services;
 Prescribing in primary care.

Coe N, Purvis J (2001) Report of the nineteenth round of panels held in September-October 2000. Somerset Health Panels Report, Somerset Health Authority.

this report covers the following topics: Resuscitation of patients;
 Services for elderly people.

Coe N, Purvis J (2001) How patients should be involved in decisions made about their health care. Special Somerset Health Panel Report, Somerset Health Authority.

Coe N, Purvis J (2001) Report of local people's views of proposed PCG boundary changes in Chard, Langport & Ilminster. Special Somerset Health Panel Report, Somerset Health Authority.

Coe N, Purvis J (2002) Report of the twenty-second round of panels held in April-May 2002. Somerset Health Panels Report, Somerset Health Authority.

this report covers the following topics: The development of the new
 Patient Advice and Liaison Service (PALS); How to effectively
 consult with patients and the public.

Coe N, Purvis J (2002) Report of the twenty-third round of panels held in September-October 2002. Somerset Health Panels Report, Somerset Health Authority.

this report covers the topic: Men's health.

Other research reports

Coe N, Ibbs A, O'Brien J (1996) *The cost effectiveness of introducing counselling into the primary care setting in Somerset*. Somerset Health Authority.

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Coe N & Roberts J (1998) *Suicide in Somerset 1993-1996*. Somerset Health Authority.

Coe N (1999) Services for children with disabilities in Somerset: The parent's perspective. Somerset Health Authority.

 also presented: Coe N (October 2000) Services for children with disabilities: The parent's perspective. European Conference:
 Qualitative Research

Coe N & Pearson V (1999) Complementary therapy in primary care in Somerset:

Access to services and public perceptions. Somerset Health Authority.

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Appendix 4: Esteem impacts

Organisation	Group	Role	Date
Industry and Parliament	Houses of Parliament Policy Breakfasts	Invited to join a small group (10 NHS participants)	2011 - current
Trust		to discuss policy topics with with MPs/Lords e.g.	
		October 2011 topic: "Can we achieve a democratic,	
		patient-centered healthcare system?"	
Guardian Newspaper	Online live discussion	Expert on the panel. February 2013 topic: "Seeking patient feedback in the NHS"	2013
Department of Health	National Institute for Health Research Involvement for Access Project Board	NHS trust representative for England	2012- current
Department of Health	National Institute for Health Research Management Oversight Board	NHS R&D Management representative for England	2007 – current
Department of Health	National Institute for Health Research Support External Reference Group	NHS R&D Management representative for England.	2009 - current
	·	Embedding in R&D national implementation project	
		lead.	
		Invited speaker at various national conferences/	
		meetings	
Department of Health	National Institute for Health Commercial Research Exemplar Project	Senior NHS Leader representative	2011 - current
Department of Health	National Institute for Health Research Information Systems Programme Board	NHS R&D Management representative for England	2007- 2009
Measures of Processes	Working Group.	Expert member	2003
of Care (MPOC)	Resulted in the publication: H. McConachie, S.		
Questionnaire UK	Logan (2003) Validation of the measure of		
Validation	processes of care for use when there is no Child		
	Development Centre. Child: Care, Health and		
	Development 29 (1), 35–45.		
NHS R&D Forum	Forum Representatives Group	Nationally elected representative for South West	2005- current
	User and Carer Working Group	since 2005	
	Research Governance Working Group		
North Bristol NHS Trust	Research Foundation (Charity No. 248189)	Trustee	2008 - current

Appendix 5: Statement of contribution

I confirm this work is all my own work and has been not been or is intending to be submitted for any other academic award.

Two of the papers submitted for this award are jointly authored. I have provided information on my contribution to each below:

- a) Oliver MA, Pearson N, Coe N, Gunnell D. (2005) Help seeking behaviour in men and women with common mental health problems: Cross-sectional study. *British Journal of Psychiatry*. 186, 297-301
- I designed and oversaw the delivery of the original study and preceding pilot study that provided the data for this paper. I also supervised the first author of this paper during data collection and writing up. This paper was drafted by the first author and revisions made by all authors.
- b) Coe N, Purvis J, Barnes M. (2000) A method for involving users in the accreditation of cancer services. *Clinical Governance Bulletin*. 1(1), 4-6
- I was the lead author for this paper. I provided methodological advice in the development of the method of user involvement and oversaw the development of the initiative. I also delivered the training to patients described within the paper.

Appendix 6: Training requirement

I have achieved the 60 credits M-level training requirements as follows:

Credits	Level	Module
20	M	Evidencing Work-based Learning Module (UZVRFG-20-M)
		"Development of a theoretical framework"
40	M	Accreditation of prior learning (UZURBD-40-M)
		MSc Social Research (University of Plymouth) Dissertation
		"Services for children with disabilities: The parent's
		perspective"