‘Are women making informed choices with regard to Combined Ultrasound & Biochemical (CUB) screening in the first trimester of pregnancy?’
Major Research Project & Research Portfolio.

Part One

(Part two bound separately)

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Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology.

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First Year Audit:

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In memory of my Dad.
It has been a long road,
I hope you would be proud of me.

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Chapter 1

First Year Audit Project

An examination of referral characteristics to the Older Adult Psychology & Neuropsychology services in Dumfries & Galloway, as a means of providing baseline measures for forthcoming organisational change.

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Major Research Project Systematic Literature Review submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology.

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Executive Summary

There has been increased emphasis on the importance of mental health service provision for older adults in the United Kingdom, since the inception of the *National Service Framework for Older People* (Department of Health, 2001). The present audit aimed to describe the characteristics of the population referred to the Older Adult Psychology and Neuropsychology services in Dumfries & Galloway, to provide baseline measures for forthcoming organisational change. This was a retrospective audit describing 4 years of referral data, between the 1st January 2001 and 31st December 2004, with particular focus on those from General Practitioners. The referral characteristics were generally as expected, however the overall rates of referral were low (1.13% to 1.91% of the population depending on area). There were also proportionately fewer referrals from Community Mental Health Teams (CMHTs), than hoped by clinicians within the service. Hence the audit recommends that means of increasing awareness of the service amongst possible referrers are found, and that links with the CMHTs are strengthened.

Background

There has been increased emphasis on the importance of mental health service provision for older adults in the United Kingdom, since the inception of the *National Service Framework for Older People* (GRO, 2001). This report called for national standards for service delivery for older people with mental health difficulties, stating that "the majority do not come into contact with specialist mental health services". In addition, the *Priorities & Planning Framework 2003-06* (Department of Health, 2003) hoped to ensure that protocols be put in place "across all health and social care systems for the care and management of older people with mental health problems".

These reports gained weight in light of the *Mental Health of Older People Report*, which asserted that of those aged 60-74 years; one in ten had a common mental disorder. One in twelve had visited their General Practitioner about a mental health problem, and three in four about a physical health problem in the preceding year (National Statistics, 2003). This high rate of presentation for physical health difficulties is important, as the *Liaison Psychiatry and Psychology Needs Assessment Report* suggested that psychological needs in the physically ill are often unrecognised (NHS Education for Scotland, 2004). In addition the *Psychology Advisory Committee Briefing Paper* (CMO, 2003) stated that functional mental health problems in older people are commonly under-detected and under-treated.

In terms of existing psychological services, both the *Division of Clinical Psychology Briefing Paper 5* (British Psychological Society, 2003) and the *Clinical Psychology Workforce Planning Report* (NHS Education for Scotland, 2002) identified a dearth of Clinical Psychology input to older adult services, which, if available, are often provided by a single clinician. The Workforce Planning Report also acknowledged the difficulties of a one-clinician service, particularly one in a large rural area. For present

purposes, this is important, as 53.8% of the population of Dumfries & Galloway reside in remote small towns or rural areas (Public Health (2003).

At a local level, Dumfries & Galloway (D&G) has the second highest mean age and joint highest median age population in Scotland (Census, 2001). Weighill (2004) stated that 19% of the total population of D&G are over 65 years, and called for "seamless services – careful planning, audit and liaison". It appears vital that unmet needs be addressed, as *Future issues in population and health care* projected that the older adult population of D&G will rise to 24% by 2016 (Carnon, 2002).

The characteristics of the older adult population in D&G differ in some important respects from other areas, as *Older People with mental health problems* stated that D&G has more dementia sufferers per head of population, than any other area in Scotland, and that 10-15% of these present with comorbid depressive symptomatology (NHS Dumfries & Galloway, 2003).

Therefore, it seems that some organisational change is required to meet the needs of such a large component of the population. The *Model of service – strategy: mental health for older adults,* stated that in order to provide a good level of psychology service in all tiers of older adult care, two A grade Clinical Psychologists are required in addition to 3 Clinical Psychology Trainees who will take up post shortly (Department of Psychological Services & Research, 2004). It is hoped that having a more obvious psychology presence in individual locality areas, will address issues outlined in *The planning, organisation and delivery of joined up services for those with dementia and their carers,* which stated that General Practitioners value accessible services (Scottish Executive, 2004).

Local Context

The service being audited is the Older Adult Psychology service, within the Department of Psychological Services and Research. Dumfries & Galloway has a population of approximately 147,000 people. The department serves four geographical localities, Annandale & Eskdale, Nithsdale, Stewartry and Wigtownshire. Over the last four years the service has comprised solely of one 0.9wte B grade Clinical Psychologist. There is also a Neuropsychology service, consisting of 0.5wte B grade Clinical Neuropsychologist.

There is some liaison with four Community Mental Health Teams which consist of 3.0wte Consultant Psychiatrists, 14wte Community Psychiatric Nurses, Social Workers and Occupational Therapists. The proposed service developments intend that one Flexible Trainee Clinical Psychologist be placed in each CMHT. The CMHTs accept referrals directly from GPs, but also from the Psychology service where appropriate.

Aims of the audit

1. To describe the characteristics of the population referred to the Older Adult Psychology service over the last four years, so that this may act as a baseline measure for forthcoming organisational change.
2. To examine patterns of referrals of older adults to the Neuropsychology service, as this is considered to be a complementary service to that of the Older Adult Psychology service.
3. To look specifically at patterns of General Practitioner (GP) referrals to the Older Adult service over the last four years. This will involve comparing referral rates to the Older Adult populations (from GP lists) for each practice. The purpose of this is

to act as a baseline for service change, and to determine which practices should be prioritised in terms of increasing awareness of the service.

Methodology

Design

This was a retrospective audit describing 4 years of referral data to the Older Adult Psychology service, between the 1st January 2001 and 31st December 2004 (n = 447). A descriptive account of referral characteristics including referring agent, geographical area of residence, patient age and gender was provided. Primary diagnosis, as decided by clinician at end of treatment, was also given. Data pertaining to GP referrals were extracted, and separated by geographical area then individual GP practice.

All data were extracted from the 'Patient Management System' (PMS), a Microsoft Access system used routinely by the department. No measures were used in addition to the routine data collection procedures. Population data used were those of the Public Health records of NHS Dumfries & Galloway (2003).

Procedure

Referral pathways and routine data collection;

Referrals are received centrally, and allocated to a service as indicated in figure 1 below.

INSERT FIGURE 1 ABOUT HERE

Once a referral has been allocated to a clinician, administrative staff create a file, and enter referral data onto the Patient Management System. Both services have short waiting times, generally no longer than two months. Once a case is discharged, a 'Discharge Summary Form' is completed, which requests that the clinician enter up to five diagnoses using the

Diagnostic & Statistical Manual IV codes (APA, 1998). This form is passed onto the administrative staff, who enter this information onto the PMS. However, at present only one diagnosis is entered onto the system with regularity. This has implications for subsequent reporting of data, which is fully discussed in the limitations section.

Sampling Strategy;

Of the 447 referrals received by the Older Adult service, when examining referring agents, 6 cases were excluded as no referrer was given (1.3%). Upon inspection of diagnoses, 60 cases were excluded as none was provided (13.4%). Of the 441 cases where referring agent was given, 190 came from GPs (43%).

Data Collection Procedures;

In fulfilling **Aim 1** of the audit, data were extracted from the PMS by using the standardised search proforma, filtering by referral date, 01/01/01 to 31/12/04 (n = 8024). The data were then filtered by age 65+ years (n = 797) and referrals to the Older Adult Neuropsychology service excluded (n = 350). The resulting data (n = 447) was exported into a Microsoft Excel format to allow examination of referral characteristics.

For **Aim 2** of the audit the Neuropsychology referrals (n = 350), were examined and sorted by referring agent, then by area. It was the intention to examine distribution of GP referrals to this service specifically, but this was not performed due to the small sample size (n = 21).

In addressing **Aim 3** of the audit, the remaining data above (n = 447) were sorted by referring agent, and the GP referrals (n = 190) extracted. These were then sorted by area, then GP practice.

Results

Aim 1: Describing the characteristics of referrals made to the Older Adult service

Of the 447 referrals made to the service, 304 (68%) were female and 143 (32%) male. The mean age of the sample was 74 years (SD = 7.1) as illustrated in table 1 below.

INSERT TABLE 1 ABOUT HERE

The greatest proportion of referrals came from GPs (42.51%) and CMHTs (24.16%). There were six excluded cases where no referring agent was stated. Of the 21 cases where the referrer was given as 'Psychologist', 12 were transfers from one clinician to another, for example the Consultant Clinical Psychologist to a Trainee. See table 2 for referral sources.

INSERT TABLE 2 ABOUT HERE

As shown in table 3 below, the most common diagnoses made were depression (21.00%), anxiety (18.00%) and adjustment to illness (15.00%). There were 60 exclusions made, where no diagnosis was given.

INSERT TABLE 3 ABOUT HERE

Upon inspection of the data, it appears that Nithsdale referred the greatest percentage of their population (1.91%), followed by Stewartry (1.34%), Annandale & Eskdale (1.32%) then Wigtownshire (1.13%) – see table 4. However, since the differences were small, it was presumed that inferential statistics would not provide any further information.

INSERT TABLE 4 ABOUT HERE

Aim 2: To examine referrals to the Older Adult Neuropsychology service.

As illustrated in table 5, the greatest proportion of referrals came from Community Mental Health Teams (64.86%) and Medical Practitioners (17.14%).

INSERT TABLE 5 ABOUT HERE

It appears that Nithsdale referred the greatest percentage of their population (1.69%), followed by Wigtownshire (1.02%), Stewartry 1.01%) then Annandale & Eskdale (0.69%). See table 6 below.

INSERT TABLE 6 ABOUT HERE

Aim 3: To look specifically at patterns of General Practitioner (GP) referrals to the Older Adult service from 01/01/01 – 31/12/04.

The following data describe referral rates segregated firstly by geographical area, then by individual practice. In all cases, upon inspection of the data, it was felt that inferential statistics would not be appropriate due to small differences between groups, and that a more descriptive account be utilised. Upon an eyeball test of the data, it appears that GPs in Annandale & Eskdale referred the greatest percentage relative to their population (0.74%), followed by Nithsdale (0.68%), Stewartry (0.65%) and Wigtownshire (0.40%).

INSERT TABLE 7 ABOUT HERE

When presented in graphic format, figure 2 below demonstrates that the lowest proportion of referrals, if segregated into groups of five, came from surgeries 4j (0.14%), 2i (0.11%), 4i (0.08%), 2h (0%) and 4h (0%). For further information regarding list sizes of individual practices, please see appendix 1.2.

INSERT FIGURE 2 ABOUT HERE

Discussion

Aim 1

The initial aim of the audit was to describe the characteristics of the population referred to the Older Adult Psychology service over a four-year period, to provide baseline measures for forthcoming organisational change. Over this period, there were a total of 447 referrals to the service (average of 112 referrals per year), which seems low in a population with nearly thirty thousand older adults. This is a concern given that the 'Mental Health of Older People report'(National Statistics, 2001) stated that one in ten of those aged 60-74 have a mental health problem. This finding may lend support to local initiatives focusing on Mental Health Promotion, so that individuals and services are better informed with respect to psychological difficulties in older adults.

The results suggested that there may be a trend for more females to be referred than males, a proportion of which may be accountable to differences in life expectancy.

The results suggest that the main referring agents were GPs, followed by CMHTs. Though the GPs rate was as expected by the clinicians in the service, that of the CMHTs was lower than hoped, which may lend support to the 'Model of service strategy' (NHS

Dumfries & Galloway, 2004) document which stresses the need for a visible psychology presence within CMHTs.

The most common diagnoses given to patients were depression and anxiety. This is in line with general prevalence rates stated in the 'Older People with Mental Health Problems' report (NHS Dumfries & Galloway, 2003). It is reassuring that the third most common diagnostic group involved problems adjusting to physical illness, given that the 'Liaison Psychiatry & Psychology Needs Assessment Report' (NES, 2004) suggested that psychological needs in the physically ill are often unrecognised.

In terms of geographical distribution of referrals, the raw data suggested that the greatest proportion came from Nithsdale, followed by Annandale & Eskdale, Stewartry and finally Wigtownshire, which was as expected by the service. When the data was adjusted for the older adult populations, it appeared that Stewartry was perhaps out-referring Annandale & Eskdale. However, the differences between all four areas were minimal. The higher referral rate from Nithsdale, may be interlinked with accessibility of services, as the department is based in this locality.

Perhaps most important, is the fact that referral rates ranged only from 1.13% to 1.91% of the population of each area, which appears to support the findings of the National Service Framework for Older People (DOH, 2001), that the majority of older people with psychological difficulties "do not come into contact with specialist mental health services".

Aim 2

The penultimate aim of the audit was to examine patterns of referrals of older adults to the Neuropsychology service. The low referral rate found in the Older Adult Psychology service appeared to be repeated, in that there were 350 cases referred over the period audited (an average of 87 cases per year). The finding that the majority of referrals

came from CMHTs and Medical Practitioners was expected by clinicians. The results also provide support for the fact that referrals from GPs were lower than desired, and that perhaps greater information as to the role of the service may be required. Particularly when we consider that Dumfries & Galloway has more dementia sufferers per head of population than any other area in Scotland (NHS Dumfries & Galloway, 2003).

Upon examining patterns of referrals by area, Nithsdale referred the greatest proportion followed by Wigtownshire, Stewartry and Annandale & Eskdale. This pattern was not greatly changed by adjusting the data for population. The slightly lower rate of referrals from Stewartry was unexpected, given that there is a memory clinic run regularly in this area.

Aim 3

The final aim of the audit was to examine patterns of General Practitioner (GP) referrals to the Older Adult service over a four-year period. The purpose of this was firstly, to provide baseline information in view of forthcoming service development, and secondly, to identify which specific surgeries should be targeted primarily in terms of increasing awareness of the service.

The low referral rate from GPs overall (190 over four years), may be a concern, given that the National Statistics (2003) stated that one in twelve older adults had visited their GP about a mental health problem during 2003. Hence the question is one of whether older people in Dumfries & Galloway are not presenting to their GP as frequently as expected, or whether GPs are failing to refer them to specialist services. This may require further investigation. If it emerges that GPs are under-referring, this may lend support to the suggestion of the Scottish Executive (2004) that GPs value accessible services, which is not the case at present due to the limitations of a single clinician service in a rural area.

Upon inspection of area referrals, it initially appeared that Nithsdale referred the greatest proportion, followed by Annandale & Eskdale. However, when adjusted for population, it seems that Annandale & Eskdale may have referred a slightly larger percentage of their population, followed by Nithsdale, Stewartry then Wigtownshire. This pattern was unexpected by clinicians, who felt that referrals had been proportionately higher for Stewartry than other areas.

In terms of specific GP surgeries, it may be helpful to segregate these into groups of five starting with the lowest referrers, so that the already stretched resources in the service may be used more judiciously to increase awareness in individual surgeries. Hence the first group to be targeted should include Nithsdale surgeries '2h' and '2i', and Wigtownshire surgeries '4h' '4i' and '4j'. There is ongoing liaison with the local Health Promotion Officer, who may be able to assist in this endeavour. Perhaps, if by focusing on this group (and using the present data as a baseline), an increase in referrals from these surgeries is observed, it may then be rolled out to the next group of practices and so forth. Surgery '4i' is of particular concern given that it has an older adult list size of 1184, and referred only one case to the service over a four-year period.

Limitations

When examining the findings of the audit, a number of limitations must be considered. Firstly, the population statistics are two years old; hence the list sizes for each GP practice may also be inaccurate. However, the data is the most recent available, and is likely to be an underestimate rather than an overestimate.

Furthermore, during the period audited, the single clinician in the Older Adult service had an extended period of absence, which was known to have had an impact on

referral rates at the time. Perhaps it would be of interest to study this period in a future retrospective audit.

When examining characteristics of cases referred to the service, it was initially the intention to examine reasons for referral. However, it was discovered that this information was largely incomplete, and lacked utility as it was decided by administrative staff without reference to diagnostic codings. Hence the audit instead examined diagnosis, given at the end of treatment, but recognizes that this does not necessarily correspond with reason for referral.

Other limitations associated with the audit, stemmed mainly from problems with the information available via the database, as five cases did not have a referring agent, and sixty lacked a diagnosis. Whether this is a result of clinician, administrative or technical error will require further investigation. Clinicians also enter up to five diagnoses on the discharge summary form, yet it seems that over the period audit, only one diagnosis was routinely inputted for each patient. This also has implications for generalisability of the findings, as it does not allow for comorbidity (particularly of neuropsychological and mental health difficulties).

Recommendations

1. That the findings be conveyed to the local Health Promotion officer, with a view to increasing mental health awareness, in the older adult population of Dumfries & Galloway.
2. That links with the CMHTs be strengthened. This will hopefully be achieved by the proposed plans to integrate Flexible Trainees within each team. However, it may be more useful to consider more permanent psychology presence within such teams.

3. That methods of increasing awareness of the service amongst General Practitioners, be investigated, particularly in Wigtownshire, and in the surgeries highlighted by Aim 3 of the audit.
4. Furthermore, that the role of the Neuropsychology service be clarified with GPs across the region, with a view to increasing the proportion of referrals from this source, thus ensuring speedier access to the service rather than via more circuitous routes.
5. That more formal measures of referral data collection be devised. Perhaps the service should begin to utilise the Clinical Outcome and Research Effectiveness system (CORE; Evans et al, 2000), used by other services within the department.
6. That the reliability of the database is assessed, and that more stringent procedures for data entry are agreed. There should be particular emphasis on the entry of 'reason for referral', which should be decided by clinicians rather than administrative staff, and should follow a formal coding system.

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Figure 1: Referral pathways

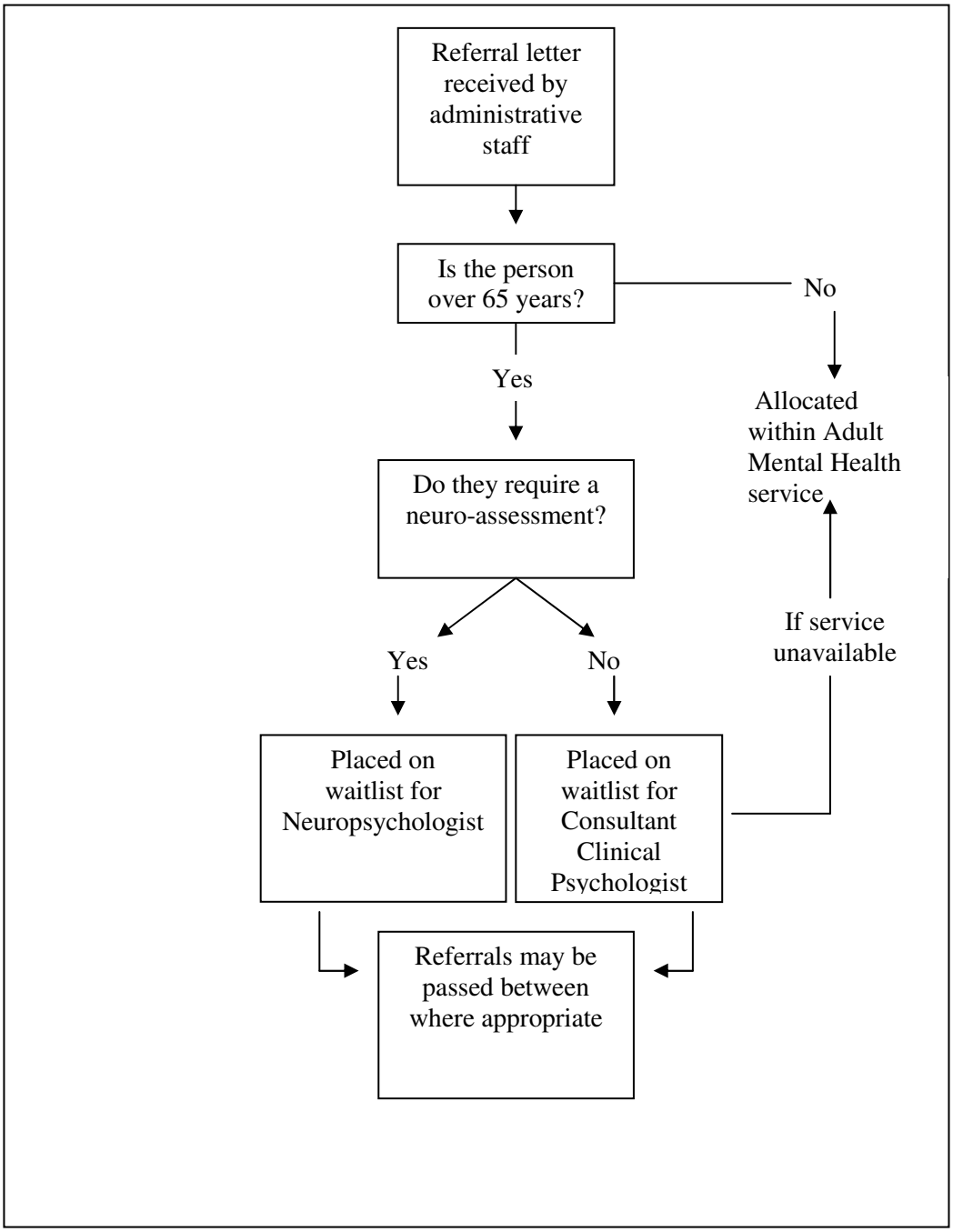


Table 1: Age and Gender distribution of referrals (n = 447)

	No. of referrals	**As % of total referrals**	**Mean age (S.D)**
FEMALE	304	68%	73 (7)
MALE	143	32%	74 (7.1)
TOTAL	447	100%	74 (7.1)

Table 2: Sources of referrals (n = 447)

Referrer	No. of referrals	As % of total referrals
GP	190	**42.51%**
CMHT (inc. psychiatry)	108	**24.16%**
Medic (inc. surgical)	34	**7.61%**
Social Services	23	**5.15%**
Nurse (GP/Day Hospital)	23	**5.15%**
Psychologist	21	**4.70%**
Nurse (Medical)	17	**3.80%**
Patient/Relative/Carer	12	**2.68%**
Other	13	**2.91%**
Missing Data	6	**1.34%**
TOTAL	447	**100.00%**

Table 3: Diagnosis given to referrals (n = 447)

Diagnosis	**No. of referrals**	**As % of total referrals**
Depression	94	**21.00%**
Anxiety	81	**18.00%**
Adjustment to physical illness	68	**15.00%**
Relationship/social issues	52	**11.50%**
Life events/bereavement	46	**10.00%**
Learning difficulties/dementia	28	**6.20%**
Sleep problems	7	**1.51%**
Sexual Difficulties	6	**1.32%**
Addiction	4	**0.88%**
Psychosis	3	**0.65%**
Eating Difficulties	2	**0.41%**
Communication/Sensory issues	1	**0.22%**
Missing Data	60	**13.37%**
TOTAL	447	**100.00%**

Table 4: No. of referrals as a percentage of the population +65 yrs for each area.

LHCC area	No. of referrals (%)	Population over 65 years	As % of population for that area
Nithsdale	199 (44.5%)	10446	**1.91%**
Stewartry	74 (16.6%)	5506	**1.34%**
Annandale & Eskdale	104 (23.3%)	7861	**1.32%**
Wigtownshire	70 (15.7%)	6173	**1.13%**
TOTAL	447 (100%)	29986	

Table 5: Referrals to the Neuropsychology service by referring agent

Referrer	No. of referrals	As % of total referrals
CMHT	227	**64.86%**
Medical Practitioner	60	**17.14%**
General Practitioner	21	**6.02%**
Other	13	**3.71%**
Charitable/Voluntary Organisation	12	**3.43%**
Psychologist	10	**2.86%**
Social Worker	7	**2.03%**
TOTAL	350	**100.00%**

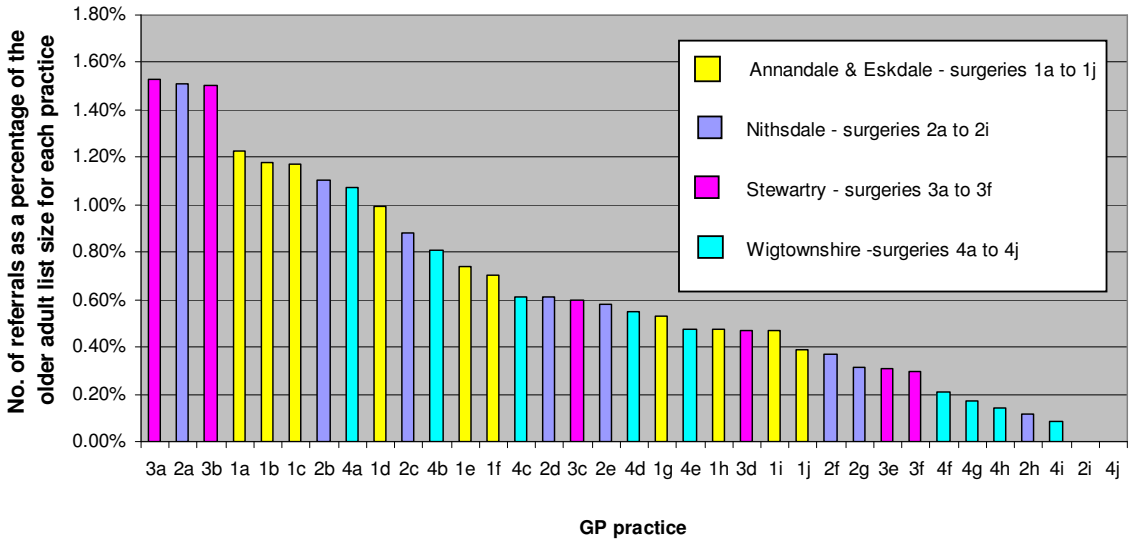
Table 6: Referrals to the Neuropsychology service by area

Area	No. of referrals (%)	Population over 65 years	As % of the area popn. over 65 years
NITHSDALE	177 (50.6%)	10446	**1.69%**
WIGTOWNSHIRE	63 (18%)	6173	**1.02%**
STEWARTRY	56 (16%)	5506	**1.01%**
ANNANDALE & ESKDALE	54 (15.4%)	7861	**0.69%**
TOTAL	350 (100%)	29986	**-**
MEAN	87.5	7497	**1.11%**

Table 7: GP referrals relative to population for each area (n = 190).

Area	No. of referrals	Popn. over 65 years	As % of popn.
Annandale & Eskdale	58 (30.5%)	7861	**0.74%**
Nithsdale	71 (37.4%)	10446	**0.68%**
Stewartry	36 (18.9%)	5506	**0.65%**
Wigtownshire	25 (13.2%)	6173	**0.40%**
TOTAL	190 (100%)	29986	-
MEAN	-	-	**0.62%**

Figure 2: GP referrals by individual practice and area



Chapter 2

Major Research Project Systematic Literature Review

Objective cognitive impairment during normal pregnancy

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Abstract:

Background: Women frequently report deterioration in cognitive functioning during the antenatal period, most notably in terms of memory and attention (Janes et al., 1999; Brindle et al., 1991; Casey et al., 1999; Sharp et al., 1993).

Objectives: This review considers whether there is evidence for *objective* changes in cognitive functioning; which domains are most affected and whether psychological/physical factors influence cognitive performance.

Inclusion criteria: Studies must involve pregnant women, utilise objective measures and be published in peer-reviewed journals.

Search strategy: The electronic databases: CENTRAL; CINAHL; EMBASE; MEDLINE; PsycINFO; BNI and Google Scholar were searched. *American Journal of Obstetrics & Gynecology* and *Human Reproduction* were hand searched. Reference lists of relevant articles were also considered. 17 papers met the inclusion criteria and are reviewed here.

Results: Studies in this area have inconsistent findings. Eight studies demonstrated that pregnant women may be impaired across a range of cognitive functions including implicit memory, explicit memory, verbal memory/learning, working memory, verbal fluency and attention. However, seven studies reported no differences between pregnant women and controls and two reported improved performance in terms of explicit memory and general cognitive functioning. One study reported that depression accounted for deterioration in cognitive performance but the remaining studies reported no correlations between psychological factors and cognitive performance. Indeed, one study reported that increased anxiety was associated with improved attention.

Conclusions: There is, at present, insufficient evidence to suggest that women are cognitively impaired during pregnancy. Other factors, such as the role of fetal sex, should be considered.

Cognitive performance during pregnancy is an area which has attracted substantial media interest over the last decade. This has, in part, been precipitated by a study conducted by Holdcroft et al. (1997), whose findings indicated a postpartum increase in brain volume, but were misinterpreted by the press to suggest a decrease in brain volume during pregnancy. The study, however, suffered from a number of methodological flaws. The media interest perhaps stemmed from the fact that these findings, although misinterpreted, seemed to resonate with the experiences of women. Indeed, current literature is awash with anecdotal reports of 'baby brain'. Burgoyne (1994), for example, described experiencing a "catastrophic deterioration of neuronal function". Anecdotal reports cannot be deemed to be representative of pregnant women as a group. In light of this, several authors attempted to adopt more systematic approaches to documenting subjective experiences of cognitive change. In one of the earliest studies, Jarrahi-Zadeh et al. (1969) found that 12% of a sample of expectant mothers complained of 'mental fogginess'. Poser et al. (1986) found that, in a study of professional women, over 80% reported increased forgetting, with reading difficulties, confusion, disorientation and distractibility listed as other common difficulties. Parsons & Redman (1991) conducted a retrospective study of 236 primiparous women within three days postpartum. Over half of the sample reported deterioration in concentration, remembering things and absent-mindedness during the last trimester of pregnancy. These results have been supported by more recent replications using a variety of methods (Janes et al., 1999; Brindle et al., 1991; Casey et al., 1999; Sharp et al., 1993).

Parsons & Redman (1991) suggested that subjective studies were limited by use of retrospective design, which may have led to under/over-representation of women's actual difficulties. In addition, what women report as 'memory difficulties' may reflect other cognitive complaints. There have been few studies of the relationship between subjective

reports and objective measures in the current context. However, research into clinical depression (Reifler et al., 1982) and temporal lobe epilepsy (Vermeulen et al., 1993) suggests that subjective reports tend to over-represent objective deficits and are more reflective of psychological factors e.g. anxiety or depression. Nonetheless, such psychological factors may precipitate objective deterioration in cognitive functioning (Veiel, 1997). Indeed, psychological changes in pregnancy are well-documented, including irritability, anxiety and fluctuations in mood (Teichman, 1988; Evans et al., 2001; Johanson et al., 2000).

Other studies have failed to find support for the notion that cognitive deficits are related to psychological changes (Keenan et al., 1998), instead tending toward possible organic bases such as hormonal changes. Increased estrogen levels are said to impact upon the hypothalamus, basal forebrain and hippocampus (McEwen et al., 1997). A review by Brett & Baxendale (2001) suggested that increase in neuronal excitability, caused by estrogens, may predispose women to excitotoxicity. Progesterone levels also rise in late pregnancy and their action upon GABA receptors has been linked to drowsiness (Paul & Purdy, 1992). Glucocorticoids are also said to increase during pregnancy and have been linked to hippocampal activity (De Kloet et al., 1994). Silber et al. (1990) reported that oxytocin levels rapidly increased prior to delivery. However, the authors reported no relationship between oxytocin levels and objective cognitive functioning. Other authors e.g. Janes et al (1999) have focused upon the role of sleep disturbance. However, Janes et al. (1999) found that although self-reports of sleep change were related to subjective memory change, they were unrelated to objective performance.

In light of the difficulties with subjective reports, there emerged a need for research designs implementing reliable and valid objective measures. The findings from such studies were not equivocal in that some reported impaired cognitive functioning (De Groot

et al., 2006; De Groot & Hornstra et al., 2003; De Groot et al., 2003; Silber et al., 1990; Keenan et al., 1998; Brindle et al., 1991) whereas others failed to find such impairment (Casey et al.; 1999, Harris et al., 1996; Christensen et al., 1999; McDowall et al., 2000; Vanston et al., 2005; Casey, 2000; Crawley et al., 2003). Indeed, one study reported improvement in cognitive performance during pregnancy (Christensen et al., 1999).

These studies tended to focus upon memory performance, with some reporting deficits in implicit (e.g. Brindle et al., 1991) and explicit memory (e.g. Keenan et al., 1998) and others finding implicit (e.g. McDowall et al., 2000a) and explicit memory to be relatively unaffected during pregnancy (e.g. Christensen et al., 1999). Of the few studies examining attention, some found deficits (e.g. De Groot et al., 2003), whilst others did not (e.g. Crawley et al., 2003).

The disparity in findings raised the question of whether different cognitive functions are affected at different stages of gestation. The majority of the objective studies focused on late pregnancy, however, with only a few testing women within the first trimester (Vanston et al., 2005; Casey et al., 2000; Schneider et al., 1989; Keenan et al., 1998; Casey et al., 2000; Schneider, 1989). The evidence is also limited by reliance on cross-sectional designs.

There are numerous demands placed upon women's cognitive functioning during pregnancy in terms of making decisions and preparation for motherhood. It therefore appears vital that consensus is reached as to whether women experience objective cognitive change. However, variance amongst participants, designs and materials make the available literature very difficult to interpret as a whole. Brett & Baxendale (2001) & Christensen et al. (1999) attempted to review the research in this area, though failed to adopt systematic approaches. To confirm a deficit within one cognitive domain, other domains must be studied to rule out a more global impairment indicative of other factors

e.g. sleep deprivation or low mood. As this has rarely been conducted within individual studies, the current review adopts a broad approach, considering the evidence across all cognitive domains. In addition, few studies control for psychological and physical health factors adequately, hence the current review aims to consider the evidence for the role of such factors in cognitive performance during pregnancy.

Objectives:

The primary objective of this review was to assess whether objective cognitive changes are observed during normal pregnancy. A secondary objective was to assess which specific areas of cognitive functioning were most affected by pregnancy, if any. A final objective was to assess whether psychological factors (e.g. mood, anxiety, stress) or physical-health factors (e.g. sleep, wellbeing) were known to influence cognitive functioning.

Criteria for considering studies for this review:

Types of studies:

Cross-sectional and longitudinal studies were considered. As randomised controlled trials are not possible in this context, a prospective longitudinal design using those who fail to become pregnant as controls was considered optimal. Studies published in peer-reviewed journals were included, to the exclusion of unpublished work. Studies presented in languages other than English were excluded.

Types of participants:

No formal age restrictions were applied, though the natural age limitations of fertility dictated the range. No limitations were placed upon women in terms of parity, educational, socio-economic status, employment, medical/psychiatric history. As previous research suggested that different cognitive functions may be affected at various stages of pregnancy, no limitations were placed upon length of gestation.

Methodological considerations and types of outcome measures:

No limitations were placed as to the type of measure or method of presentation. Though limiting comparability of results and possibility of meta-analytic methods, this allowed for exploration of all cognitive domains previously investigated. Studies using only subjective measures of cognitive functioning were excluded.

Search strategy for identification of studies:

The following databases were used in order to search for relevant articles: CENTRAL – Cochrane Central Register of Controlled Trials (3rd Quarter, 2005); CINAHL (1982-2005); EMBASE (1988-2005); MEDLINE (1986-2005); PsycINFO (1985-2005)

and BNI (1985-2005). The following search terms were inputted into above databases: [pregnan*] or [matern*] or [prenatal] or [antenatal] or [perinatal] or [peripartal] or [expectant] or [primigravid] or [multigravid] or [trimester] AND [cogniti*] or [neuropsychological] or [brain] or [memory] or [amnesi*] or [attention*] or [information processing] or [executive function*] or [concentration] or [learning] or [thinking] or [word finding]. The database Google Scholar was also searched, using the same search terms.

Results of a Web of Science search indicated that articles were most commonly published within *American Journal of Obstetrics & Gynecology* and *Human Reproduction.* These journals were then hand searched for relevant articles. The reference lists of relevant articles were also considered. In total, 17 studies were included in the current review. Results of the search strategy are detailed in appendix 2.2 and studies included in 2.3.

Quality assessment protocol:

Studies were assessed for quality using an assessment protocol created from those of Cho & Bero (1994) and the revised version of the Scottish Intercollegiate Network 'SIGN 50: A guideline developer's handbook' (SIGN, 2004). The protocol is shown in appendix 2.4. Previous quality assessment tools created by the Cochrane collaboration were not appropriate in the current context, as they consider the randomised controlled trial to be the gold standard in study design (Cochrane, 2006) though studies within the current review may randomly select pregnant participants from a given population, there are no treatment conditions to consider and true randomisation to pregnant versus control groups would not be feasible for obvious reasons. Though the protocol created by Cho & Bero (1994) was originally designed to assess quality of drug trials, particular emphasis was placed upon study design, allocating up to 5 points for an optimal design. In the present review, this was felt to be of primary importance, with the gold standard design being a

prospective longitudinal study of a group of women planning to become pregnant and following them through their pregnancy (using women who fail to become pregnant as controls). It was felt appropriate to adapt the protocol of Cho & Bero (1994) and to combine it with that of SIGN 50 (2004) to ensure a range of applicable quality criteria.

Responses for the majority of the quality questions take the form of 'yes' (2 points), 'partial' (1 point), 'no' (0 points) or 'not applicable' (0 points). The total points accrued by a study are then divided by the maximum points possible, to produce a score between 0 and 1 (where 1 represents the highest quality). During the development of this protocol, Cho & Bero (1994) reported a mean quality score of 0.60 (SD=0.13, range = 0.36-0.74). Each study included was reviewed by two independent raters and perfect agreement was achieved.

Results:

Comparison of participants included in studies:

Studies varied widely in terms of the age, parity, education and trimester of pregnancy of the participants involved. Some studies failed to fully assess demographic factors and those that did presented their data in such a variety of formats, that it was considered more appropriate to present the information in a table (see table 1).

Comparison of cognitive domains examined and objective measures used in studies:

Memory – implicit versus explicit:

Subdivisions into different aspects of memory differ depending upon the theoretical stance adopted. Five studies (McDowall et al., 2000a; McDowall et al., 2000b; Keenan et al., 1998; Brindle et al., 1991; Christensen et al., 1999) focused upon implicit versus explicit memory. Implicit memory was measured using word fragment/stem completion

priming (McDowall et al., 2000a; Keenan et al., 1998; Brindle et al., 1991; Christensen et al., 1999) or category generation tasks (McDowall et al., 2000b). Explicit memory was measured using semantic cued recall (McDowall et al., 2000a; Christensen et al., 1999), graphemic cued recall (McDowall et al., 2000b) and recall/recognition of item lists (Brindle et al., 1991; Christensen et al., 1999). Keenan et al. (1998) used both the logical memory subtest of the Wechsler Adult Intelligence Test – Revised (WAIS-R) and the California Discourse Memory Test. Objective measures used in studies are detailed in appendix 2.5.

Two further studies (Janes et al., 1999; Casey et al., 1999) included measures of implicit memory (using word-stem completion) and explicit memory (asking a set of questions relating to video footage). Harris et al. (1996) used the logical memory task of the WAIS-R to assess explicit memory. Janes et al. (1999) also included a measure of working memory - backward digit span of the Wechsler Adult Intelligence Test – 3rd edition (WAIS-III). Casey et al. (1999) adopted a broader approach to memory, exploring incidental (unexpected repeat of the video task aforementioned), semantic (recall of three category lists), short-term (digits forward subtest of WAIS-III) working (digits backward subtest of WAIS-III and a reading task) and prospective memory (asking participants to telephone one week later).

Memory – other:

Four studies measured verbal memory/learning using either the Visual Verbal Word Learning Task (De Groot et al., 2006), California Verbal Learning Task (Vanston et al., 2005), a text memory task (Crawley et al., 2003) or the Selective Reminding Test (Condon et al., 1991). De Groot & Hornstra (2003) studied intentional learning using a Visual Verbal Word Learning Task and semantic memory using the FLU fluency Test.

Vanston et al. (2005) examined object location memory using Silverman-Eals Test and working memory using a battery of Listening Span, Computation Span, Shepard-Metzler Mental Rotation tasks. Silber et al. (1990) tested visual memory using The Benton Test and The Pattern Memory Test. This study also included measures of learning and retention, namely the Associate Learning Test and Late Recall Test. Casey (2000) examined short-term memory (though this is widely considered to be an unhelpful concept) using digits forward and backward of WAIS-III. Working memory and semantic memory were also examined, though the exact nature of the test used was unclear.

Attention, speed of information processing and perceptual speed:

Six studies reported including measures of attention using a finger precuing task (De Groot et al., 2003), The Simple Reaction Time Test (Silber et al., 1990), a dot probe task (Christensen et al., 1999), a Paced Auditory Serial Addition Test (Harris et al., 1996) and a letter cancellation task (Harris et al., 1996). Crawley et al. (2003) employed both the Stroop Colour-Word Interference test and Halsted Reitan Neuropsychological Test Battery, respectively measuring focused and divided attention.

In terms of speed of information processing, both De Groot et al. (2006) and De Groot & Hornstra et al. (2003) employed a battery of tests comprising: the Concept Shifting Test, The Stroop Colour-Word Interference test and Letter Digit Substitution Test. Condon et al. (1991) also utilised the Stroop test. Finally, Vanston et al. (2005) used symbol search and digit-symbol coding subtests of the WAIS-III as measures of perceptual speed/accuracy.

General cognitive ability:

Seven studies included measures of more general cognitive ability using the Controlled Oral Word Association Test – FAS (McDowall et al., 2000a; McDowall et al., 2000b); National Adult Reading Test (Keenan et al., 1998; Christensen et al., 1999); Vocabulary subtest of the WAIS-R (Keenan et al., 1998); vocabulary/reasoning subtests of the Shipley Institute of Living Scale (Casey, 2000); digit symbol subtest of WAIS-R and a Trail Making Task (Harris et al., 1996). Schneider (1989) attempted to adopt a broader approach, implementing tests of number comparison, digit symbol, arithmetic, digit span and comprehension (the authors failed to state the source of their measures, though they appear to be components of the WAIS).

Comparison of materials used to assess psychological/physical health in studies:

Materials utilised in the assessment of mood, anxiety, stress, emotional and physical wellbeing appear to vary across studies. They are therefore summarised in table 2 for ease of interpretation.

Comparison of results of studies:

Objectives 1 & 2 – Is there evidence for cognitive impairment in pregnancy? If so, which cognitive domains are most affected?

Ten studies reported significant differences between pregnant women and controls, most commonly indicating impairment in verbal memory/learning in pregnant women (Condon et al., 1991; Silber et al., 1990; De Groot et al., 2006; De Groot & Hornstra et al., 2003). Pregnant women were reported to be impaired in terms of implicit memory (Brindle et al., 1991), explicit memory (Keenan et al., 1999), working memory (Janes et al., 1999), verbal fluency (Janes et al., 1999) and attention (De Groot et al., 2003; Silber et al., 1990).

However, two studies reported that pregnant women's performance was superior to that of controls in terms of explicit memory (Christensen et al., 1999) and general cognitive functioning (Scheider, 1989). Seven studies reported finding no differences in cognitive performance between pregnant women and controls, on any of the measures used (Mc Dowall et al., 2000a; Mc Dowall et al., 2000b; Vanston et al., 2005; Casey et al., 2000; Crawley et al., 2003; Casey et al., 1999; Harris et al., 1996). These results will be discussed in more detail in relation to each cognitive domain. Results are presented in appendix 2.5 and 2.7 in relation to review objectives. Eleven studies examined subjective reports of cognitive impairment and although outwith the scope of this review, these are summarised in appendix 2.6.

Memory – implicit:

Significant findings: Brindle et al. (1991) found that primigravid women were significantly impaired relative to controls – particularly during the 2nd trimester. However, this difference was not replicated for multigravid women.

Non-significant findings: Six studies reported no significant differences between pregnant women and controls (McDowall et al., 2000a; McDowall et al., 2000b Keenan et al., 1998; Christensen et al., 1999; Janes et al., 1999; Casey et al., 1999).

Memory – explicit:

Significant findings: Christensen et al. (1999) found that the performance of women in the 3rd trimester was superior to those in the 2nd trimester or controls. However, these results should be interpreted with caution due to inclusion of pregnancy-related words. In contrast, Keenan et al. (1998) found that controls performed significantly better than pregnant women during the 3rd trimester (though not in the 2nd trimester/postpartum).

Non- significant findings: Seven studies reported finding no differences between pregnant women and controls (McDowall et al., 2000a; McDowall et al., 2000b; Brindle et al., 1991; Christensen et al., 1999; Harris et al., 1996; Janes et al., 1999; Casey et al., 1999).

Memory – other:

Significant findings: In terms of working memory, Janes et al. (1999) found that pregnant women were significantly impaired relative to controls on the digits backward test of the WAIS-III, though not on a test of reading span. Vanston et al. (2005) found that the performance of women carrying female fetuses was impaired in comparison to male, which may have implications for interpretation of other studies. De Groot & Hornstra et al. (2003) reported that pregnant women's performance was impaired on a test of verbal fluency, relative to controls, when education and parity were controlled. In terms of verbal memory/learning, two studies found that pregnant women were impaired relative to controls (De Groot et al., 2006; De Groot & Hornstra et al., 2003). Condon et al. (1991) found that pregnant women were poorer on two of three subtests of a selective reminding test. Silber et al. (1990) found that women's performance on the Associate Learning Test improved postpartum, relative to performance during pregnancy. As this difference was not seen in controls, it was interpreted as evidence that women were impaired during pregnancy, though between-groups comparison would be required to assess this. No differences were found on the Late Recall Task.

Non-significant findings: Three studies failed to find differences in working memory of pregnant women versus controls (Casey et al., 1999; Vanston et al., 2005; Casey et al., 2000). Studies reported no differences on tests of short-term memory (Casey et al., 1999; Casey et al., 2000), incidental memory (Casey et al., 1999), prospective

memory (Casey et al., 1999), object location memory (Vanston et al., 2005) or visual memory (Silber et al., 1990), verbal fluency (Casey et al., 1999; Casey et al., 2000) and verbal memory/learning (Vanston et al., 2005; Crawley et al., 2003).

Attention, speed of information processing and perceptual speed:

Significant findings: De Groot et al. (2003) found that pregnant women's priming was significantly impaired, relative to controls, at week 36 of pregnancy. However, no significant differences were found at week 14, 17 or 26. Silber et al. (1990) reported that pregnant women showed a significant improvement on a reaction time test postpartum, compared to week 36 of pregnancy (such improvement was not seen in controls). Though this may be indicative of a return to baseline functioning, between group comparison is required.

Non-significant findings: Harris et al. (1996) reported that the pregnant group appeared to be impaired relative to controls on the PASAT, but not on letter cancellation. However, this difference only reached significance postpartum. Two studies reported finding no significant differences between attention pregnant women and controls (Christensen et al., 1999; Crawley et al., 2003). All studies reported that the speed of information processing of pregnant women did not differ significantly from that of controls (Condon et al., 1991; De Groot et al., 2006; De Groot & Hornstra et al., 2003). Vanston et al. (2005) failed to identify any visuo-perceptual differences in performance between pregnant women and controls.

General cognitive ability:

Significant findings: Schneider et al. (1989) suggested a gradual improvement in performance as pregnancy progressed. However, these results are of limited reliability due to lack of controls or formal measures.

Non-significant findings: Harris et al. (1996) used digit-symbol and trail-making tasks and found that the pregnant group appeared to be poorer, but only on digit-symbol. However, this difference only reached significance postpartum. Four studies reported that the performance of the pregnant group was not significantly different than that of the control group (McDowall et al., 2000a, McDowall et al., 2000 experiment 2; Christensen et al., 1999; Casey, 2000).

Objective 3 results – whether psychological/physical wellbeing has an impact upon cognitive functioning during pregnancy.

Mood:

Significant findings: Harris et al. (1996) found that pregnant women were significantly lower in mood than controls on depressive aspects of the HADS. Keenan et al. (1998) found that pregnant women were significantly lower in mood than controls during the 2nd trimester, 3rd trimester and postpartum period, but not during the 1st trimester. However, somatic complaints of pregnancy spuriously elevated BDI scores. In addition, Christensen et al. (1999) found no significant between group differences, until dividing BDI scores into cognitive and somatic items – where somatic scores were significantly elevated in pregnant women. Results are presented in table 2 and in appendix 2.7 in relation to review objectives.

Non-significant findings: Three studies reported that pregnant women did not differ significantly from controls in terms of mood (McDowall et al., 2000a; McDowall et al.,

2000b; Casey et al., 2000) and four failed to examine between group differences (Vanston et al., 2005; Condon et al., 1991; De Groot et al., 2006; Scheider, 1989).

However, between-group comparison is not particularly meaningful in the current context, without exploration as to whether mood correlated with objective cognitive performance;

Significant findings: Harris et al. (1996) found that the degree of objective cognitive impairment was highly correlated with depression scores. Indeed, when depression was controlled for, differences in cognitive performance between pregnant women and controls became non-significant.

Non-significant findings: Five studies failed to find any significant correlations (Keenan et al., 1998; Vanston et al., 2005; Condon et al., 1991; Casey et al., 2000; Schneider, 1989). However, Vanston et al. (2005) did not report their results in full and Schneider (1989) examined trends without use of formal statistics.

Anxiety, stress and emotional wellbeing:

Significant findings: Keenan et al. (1998) found that pregnant women reported significantly higher levels of anxiety than controls during the 2nd and 3rd trimesters of pregnancy (but not in the 1st). However, closer inspection suggested that somatic items accounted for this difference, particularly in the 3rd trimester. In contrast, Casey et al. (1999) found that pregnant women reported significantly lower levels of anxiety and healthier levels of emotional wellbeing in comparison to controls.

Non-significant findings: Seven studies reported no significant differences in self-reported anxiety levels between pregnant women and controls (Casey et al., 2000; Harris et al., 1996; Christensen et al., 1999; McDowall et al., 2000a; McDowall et al., 2000b; Brindle et al., 1991; Janes et al., 1999). Studies found no differences in stress (Casey et al.,

2000) or ‘emotional health’ (Janes et al., 1999) between pregnant women and controls.

Again, exploration as to whether anxiety was correlated with objective cognitive performance must be conducted before conclusions can be drawn;

Significant findings: Brindle et al. (1991) reported significant correlations between anxiety and priming, in that those with higher anxiety levels demonstrated improved priming. The authors indicated that production of benzodiazepines by the mammary glands may mean that pregnant women have lower levels of anxiety and therefore poorer priming. However, this suggestion is not borne out by their failure to detect between-group differences.

Non-significant findings: Three studies found that neither anxiety (Casey et al., 2000; Keenan et al., 1998), nor stress (Casey et al., 2000), was correlated with objective cognitive performance.

Physical health and sleep:

Significant findings: Janes et al. (1999) found that primigravid women were more likely to report a recent deterioration in sleep than were controls. Casey et al. (1999) reported a similar finding, though the results are limited by the inclusion of new mothers.

Non-significant findings: Six studies reported taking ratings of physical wellbeing, yet none reported differences between pregnant women and controls (McDowall et al., 2000a; McDowall et al., 2000b; Casey et al., 2000; Brindle et al., 1991; Janes et al., 1999; Casey et al., 1999). Casey et al. (2000) reported no between group differences in sleep.

Only Brindle et al. (1991) studied covariance between physical health and objective cognitive performance and found no significant relationships. None of the aforementioned studies found any correlations between self-reports of sleep and objective cognitive

performance. However, two studies found significant correlations with subjective cognitive performance (Casey et al., 2000; Casey et al., 1999).

A meta-analysis of results of reviewed studies was intended but was not considered to be worthwhile. Lack of control groups; demographic differences between groups; failure to explicitly state which trimester of pregnancy women were being tested in and failure to provide standard deviations for all scores would have rendered meta-analytic results too difficult to be interpreted in a valid fashion.

Comparison of quality of studies using quality instrument:

Seven studies were identified as cross-sectional controlled studies (McDowall et al., 2000a; McDowall et al., 2000b; De Groot et al., 2003; Janes et al., 1999; Casey et al., 1999; Brindle et al., 1991, Christensen et al., 1999) and eight were cross-sectional longitudinal controlled studies (De Groot et al., 2006; Vanston et al., 2005; De Groot et al., 2003; Silber et al., 1990; Condon et al., 1991; Crawley et al., 2003; Keenan et al., 1998; Harris et al., 1996). One study was identified as a prospective longitudinal study (Schneider, 1989) and one a prospective longitudinal controlled study (Casey et al., 2000), which was considered to be the optimum design in terms of addressing the aims of the review. Quality scores are presented in table 3 and raw scores in appendix 2.8.

Of the seven longitudinal studies with controls, one study failed to test their control group on the same number of occasions as the experimental group (Vanston et al., 2005), which is important in controlling for practice effects and two studies focused on the postpartum period with only one testing point during pregnancy (Silber et al., 1990; Harris et al., 1996). Two studies failed to fully specify their research question (Janes et al., 1999; Brindle et al., 1991) and two would have benefited from altering their research designs (De Groot et al., 2003; Janes et al., 1999).

Twelve studies failed to fully report their inclusion criteria (McDowall et al., 2000a; McDowall et al., 2000b; Vanston et al., 2005; De Groot et al., 2003; Casey et al., 2000; Keenan et al., 1998; Janes et al., 1999; Casey et al., 1999; Brindle et al., 1991; Harris et al., 1996; Christensen et al., 1999; Crawley et al., 2003). In addition, ten studies failed to fully report their exclusion criteria (McDowall et al., 2000a; McDowall et al., 2000b; Vanston et al., 2005; Silber et al., 1990; Condon et al., 1991; Casey et al., 2000; Crawley et al., 2003; Schneider, 1989; Casey et al., 1999, Brindle et al., 1991; Harris et al., 1996; Janes et al., 1999).

All studies chose a reasonable control group with the exception of Schneider (1989). However, the experimental group of one study contained a substantial proportion of midwives (Brindle et al., 1991), whilst another chose women who were also taking part in a fatty acid supplementation study (De Groot et al., 2006), which has been hypothesised to prevent deterioration in cognitive functioning during pregnancy (Krauss et al., 2007).

Ten studies failed to reach the preferred sample size of over 27 participants per group (McDowall et al., 2000a; McDowall et al., 2000b; Vanston et al., 2005; Silber et al., 1990; Casey et al., 2000; Crawley et al., 2003; Keenan et al., 1998; Janes et al., 1999; Brindle et al., 1991; Harris et al., 1996). None of the studies provided sample size justification and only two provided post-hoc power calculations (McDowall et al., 2000a; McDowall et al., 2000b). Seven studies reported participant attrition (De Groot et al., 2006; Vanston et al., 2005; Silber et al., 1990; Condon et al., 1991; Casey et al., 2000; Crawley et al., 2003; Schneider et al., 1989; Keenan et al., 1998).

As true randomisation is not possible in this context, random selection from the target population was felt to be of importance. However, no studies implemented this technique. In terms of measurement bias, four studies explicitly stated that participants were blind to the hypotheses of the study (McDowall et al., 2000a; McDowall et al.,

2000b; Vanston et al., 2005; Janes et al., 1999). One study stated that both participants and investigators were blind to group membership, as the pregnant women were divided by fetal sex – which was not known until birth (Vanston et al., 2005).

Three studies could have provided more information to demonstrate the reliability and validity of measures used (Silber et al., 1990; Crawley et al., 2003; Casey et al., 1999). Casey et al (1999) adapted an existing measure, though was not explicit as to the changes.

Ten studies accounted for at least two known confounding factors in their study design – most commonly age and education. Of the remaining studies, four failed to take account of education (Silber et al., 1990; Schneider et al., 1989; Keenan et al., 1998; Brindle et al., 1991). One study reported that their control group was of significantly higher parity and education than the experimental (De Groot et al., 2003) and two found their control groups to be significantly older (Casey et al., 1999; Brindle et al., 1991). Three studies failed to include demographic factors as covariates within their analyses (Vanston et al., 2005; Keenan et al., 1998; Harris et al., 1996) though one matched cases on the basis of age and occupation (Silber et al., 1990).

In this context, it was felt to be important that studies account for other clinical/health factors within their design which may confound the results. Only two studies failed to take account of any clinical/health factors (De Groot et al., 2003; Crawley et al., 2003). Two studies excluded participants on the basis of psychiatric issues yet failed to monitor common mental health problems e.g. anxiety or depression during the study (De Groot et al., 2006; De Groot et al., 2003). One study excluded participants on the basis of medical complaints/medication usage, but failed to monitor any other factors (Silber et al., 1991). With the exception of four (De Groot et al., 2003; De Groot et al., 2003; Silber et al., 1990; Crawley et al., 2003), most studies included clinical/health factors as covariates in their analyses.

The statistical tests were reported and felt to be entirely appropriate for the majority of studies, with the exception of one which failed to fully specify the method of intraindividual comparisons used and the rationale for doing so (Silber et al., 1990). Five studies reported all significance levels or confidence intervals (De Groot et al., 2006; De Groot et al., 2003; De Groot et al., 2003; Condon et al., 1991; Christensen et al., 1999) though only one provided post hoc calculations for non-significant results (Casey et al., 2000). Schneider et al. (1989) reported full results for just one participant and attempted to infer causality within an intraindividual design.

Comparison of quality scores given by the two independent raters on the measure constructed from components of Cho & Bero (1994) and SIGN (2004) indicated that the mean quality score for reviewed studies was 0.63 (SD = 0.09, range = 0.45 – 0.78).

Other issues relating to study quality not assessed by quality instrument:

McDowall et al. (2000) was the only study to consider both direct and indirect means of assessing memory. It could be suggested that failure to differentiate modes of assessment may lead to an inability to differentiate between the effects of task and process. In addition, it could also be suggested that longitudinal studies cannot adequately measure implicit memory, as this would demand that women be unaware of the purpose of priming tasks.

Vanston et al. (2005) concluded that women's cognitive performance is selectively affected by fetal sex. However, participants in their study delivered more male babies, than female. The authors stated that perhaps more women carrying females chose not to take part due to severe morning sickness (thought to be more common in those carrying females). No other studies within the current review reported eventual fetal sex, raising issues as to the representativeness of samples.

Finally, although inclusion criteria often excluded those with psychiatric disorder, none of the studies reviewed specified how this was assessed. Some additional quality issues in relation to certain studies are provided in table 3.

Discussion

Of seventeen papers reviewed, eight claimed to demonstrate cognitive impairment during pregnancy and two reported that pregnancy confers a cognitive benefit. Few studies demonstrated clear effects and studies were generally poor in quality. It can therefore only be concluded that there is some evidence of cognitive impairment during pregnancy, but that findings are inconsistent. In relation to which cognitive domains are most affected, seven studies reported significant impairment in memory, with four studies reporting deficits in verbal memory/learning in particular. However, as most studies were guided by previous subjective reports of cognitive change when selecting measures, the studies perhaps pay insufficient attention to other areas of cognitive functioning. In terms of gestational differences, only two studies reporting significant cognitive impairment, examined women during all three trimesters, with the remaining studies focusing upon the second and/or third. Four of these studies examined the relationship between trimester and cognitive performance, with two reporting that women were only impaired in the third trimester and one reporting that women were impaired at all stages (though differences were more marked in the second trimester). Two studies reporting no significant differences studied women across all trimesters with the remainder focusing upon the second and/or third. Five studies of the seventeen studies reported that pregnant women were significantly more depressed, anxious or experienced more sleep difficulties than controls, though only one found this to be correlated with objective cognitive performance (depression accounted for differences in attention and general cognitive functioning).

However, many studies failed to examine the relationship between self-report measures and objective cognitive functioning and others found that somatic changes in pregnancy spuriously elevated scores on self-report measures.

Some limitations of this review are noteworthy. Firstly, the review excluded unpublished work or papers published in journals which were not peer-reviewed. Though some potentially interesting research findings may have been overlooked, there was no systematic method to ensure identification of such papers. Secondly, no meta-analysis of results was conducted, for reasons given earlier. Furthermore, the quality instrument was designed using aspects of Cho & Bero (1994) and SIGN (2004) to the fit the purposes of the review, hence questions as to its reliability and validity could be raised. However, it was difficult to identify a suitable measure as most existing measures treat the randomised controlled trial as the gold standard - a design inappropriate in the current context.

It was anticipated that the results of this review would provide systematic evidence as to which cognitive domains are most affected during pregnancy, what proportion of this can be attributed to psychological or physical health factors and the gestational points at which women are most vulnerable. However, with such inconclusive findings, it appears more appropriate to discuss potential areas of future research. Existing studies tended to use women's subjective reports as guidance for the cognitive domains examined, hence the majority focused upon memory. However, as women may describe difficulties across a range of cognitive domains as a 'memory' difficulty, a broader approach to cognitive assessment should be adopted in future studies. In terms of study design, longitudinal approaches would be of most benefit, particularly those using women's pre-pregnancy measures as their own baseline (though there may be difficulties in using such an approach to assess implicit memory). There exists the possibility that women may be more easily distracted or absorbed by their pregnancy, as Christensen et al (1999) found that women's

performance was superior to controls when pregnancy-related word lists were utilised. This may merit further research. As McDowall et al (2000) reported that failure to use both direct and indirect means of assessing memory, may lead to a confound between task and process, perhaps future studies may consider the types of tasks utilised more carefully. Finally, it appears imperative that researchers consider the role of fetal sex, as Vanston et al (2005) report that women carrying females were impaired relative to those carrying males.

Conclusions

Results showed that studies in this area have inconsistent findings. Eight studies demonstrated that pregnant women may be impaired across a range of cognitive functions including implicit memory, explicit memory, verbal memory/learning, working memory, verbal fluency and attention. However, seven studies reported no differences between pregnant women and controls and two reported improved performance in terms of explicit memory and general cognitive functioning. One study reported that depression accounted for deterioration in cognitive performance but the remaining studies reported no correlations between mood, anxiety, stress, emotional wellbeing, sleep or physical wellbeing. Indeed, one study reported that increased anxiety was associated with improved performance on a measure of attention. However, studies suffered from a number of methodological difficulties. In addition, Vanston et al (2005) reported that women carrying female fetuses were impaired relative to those carrying males, which would appear to merit further investigation. Overall, the current review was felt to have achieved its objective of summarising existing evidence for cognitive changes during normal pregnancy.

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Chapter 3

Major Research Project Proposal

"Are women making 'informed choices' with regard to Combined Ultrasound & Biochemical (CUB) screening in the first trimester of pregnancy?"

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Major Research Project submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology. This proposal has been subject to a number of amendments, which are detailed in appendix 3.2.

Prepared in accordance with the requirements for submission to the British Journal of Obstetrics & Gynaecology (see appendix 3.1).

Total number of text pages: 21

Summary

Background: Existing literature has identified that there appear to be significant deficits in women's knowledge of antenatal screening. On the basis of this many authors conclude that women are failing to make informed choices with regards to screening. However, current definitions dictate that informed choice occurs not merely as a result of sufficient knowledge, but by acting in line with one's attitudes despite any perceived sources of social pressure (Dormandy, 2002). Studies also suffer a number of methodological issues and in an ever-changing technological climate, are losing validity rapidly.

Objective: To investigate whether women are making informed choices with regard to a relatively new form of screening – Combined Ultrasound & Biochemical (CUB). The study hopes to extend extant literature by using more substantial criteria for the assessment of informed choice, encompassing; knowledge, attitude and perceived social pressure. It is expected that the setting and methods will be clearly defined and that the results will hold clinical utility.

Design: Prospective non-experimental.

Setting: The Queen Mother's Maternity Hospital in Glasgow.

Participants: A minimum of 64 required to achieve sufficient power.

Outcome measures: A multidimensional measure of informed choice encompassing demographic factors, all aspects of the Theory of Planned Behaviour (Ajzen, 1985) and eight areas of awareness in relation to antenatal screening as recommended by The Royal College of Obstetricians and Gynaecologists (RCOG, 1993).

Analyses: A number of regression analyses in addition to simple correlations.

Introduction

The Queen Mother's Maternity Hospital in Glasgow offers a relatively new form of Combined Ultrasound and Biochemical (CUB) screening in the first trimester of pregnancy. This has the capacity to identify those at increased risk of Down's syndrome and Trisomy 18/13 (Stenhouse et al., 2004). The ultrasound can also visually identify non-continuing pregnancies, severe neural tube and abdominal wall defects. CUBs takes place at 11-14 weeks, allowing women access to options not available at the standard 16-18 weeks e.g. surgical termination under general anaesthetic (MIDIRS, 2005).

Despite the potential benefits, the decision to undergo screening should be as informed as possible, as studies have suggested that some women regret having screening (Sandelowski,1994). There is also the potential for 'false negatives/positives', which have been found to perpetuate psychological maladjustment in parents of infants with Down's syndrome (Hall et al., 2000) or cause persisting anxiety (Oakley, 1997) respectively. There is also a paucity of research into the safety of the ultrasound aspect of the screen (Frye, 1997).

What constitutes an 'informed choice'?

In the present context, Dormandy (2002) stated that an informed choice can occur when "options are clearly presented, relevant information is given and decisions to undergo or to decline a screening test reflect the attitudes of those offered the test".

Why is informed choice important in the current climate?

There has been increased focus on informed consent since the publication of the Patient's Charter (DOH, 1991). In terms of screening in general, the United Kingdom National Screening Committee urged for a changed approach to information giving (UKNC, 2004). In addition a publication by the General Medical Council stated that ultrasound screening should be the result of an informed choice (GMC, 1999).

How informed are expectant women?

A review of 64 studies involving direct data from pregnant women, identified 5 studies involving screening at the 14th week of pregnancy (Bricker et al, 2000). Two looked at both ultrasound and serum screening, and neither looked at these when used in combination. Therefore, studies of women's knowledge in other screening contexts must be examined, as the findings may be applicable to CUB screening to an extent.

Marteau et al. (1988) developed the 'Multidimensional Measure of Informed Choice (MMIC)' to measure women's knowledge of serum screening and amniocentesis and found that women were poorly informed, particularly younger women of lower parity. Women of lower educational levels (Santalahti et al., 1998) and from ethnic minorities (Dormandy et al., 2005) have also been found to be significantly less informed.

Smith et al. (1994) found that women were highly informed about procedural aspects of serum screening for Down's syndrome but had very little knowledge outwith that. Worryingly, studies suggest that women can remain ill informed even after undergoing a screen (Green et al., 1993).

It is important to point out that misinformation does not necessarily equate to lower uptake, in fact often the contrary (Eurenius et al., 1997).

Do women make informed choices?

Many of the studies in the previous section would consider their results evidence that women do not make informed choices, as they are frequently ill informed. However, when we consider Dormandy's definition of 'informed choice', it states that attitudes must be in line with the decision and supersede (perceived) pressure from others. There are very few studies that look specifically at attitudes in the context of informed choice in antenatal care.

Dormandy et al. (2002) looked at women's decisions to have serum screening using the MMIC (Marteau et al., 1988), the attitude component of the Theory of Planned Behaviour (TPB; see appendix 3.3) and a questionnaire based on eight areas of awareness as recommended by the Royal College of Obstetricians and Gynaecologists (RCOG; see appendix 3.4). The study compared hospitals offering screens at first appointment to those requiring an extra visit and found that women made relatively informed choices, more so if the screen was available at the time.

Berne-Fromell (1984) carried out a study of women declining serum screening for spina-bifida in Norway, and found that though uptake rates were lower than in many studies, women's decisions to decline were more in line with their attitudes. However, the sample demonstrated unusually high levels of education.

Are women ill informed due to poor information-giving by services?

One difficulty with the literature thus far, is that the information women are given in relation to screening (if any) is not discussed. Goel et al. (1996) conducted a multi-centre study of women being offered serum screening and found that those given written information were better informed. Hence it is important to examine studies which actively attempt to moderate women's knowledge by provision of information.

Several studies have found it possible to improve women's understanding of serum screening (Faden et al., 1985) and ultrasound (Oliver et al., 1996) relative to controls, using an information booklet. Despite some negative content, women valued the information and uptake remained the same. Indeed, adding extra information does not require a high technology approach as Graham et al. (2000) that using touch-screen computers conferred no advantage over well-prepared information leaflets.

Difficulties with existing literature

Given that the emotional sequelae of screening outcomes have been found to be mediated by women's knowledge and that low baseline knowledge levels can be improved by the provision of relevant information by services, it appears that more research is required. The existing literature outlined above seems inadequate as many studies fail to give contextual information e.g. why/when/where procedures carried out. This is important in terms of analysis as we need to know why a screen was carried out before we can assess awareness. There is often poor description of methods and of information that women routinely receive. Perhaps more importantly, many studies have created measures specific to their service but lacking any theoretical framework. Finally, despite claiming to be investigating

levels of informed choice, few studies look beyond knowledge to more attitudinal components of this.

Of the three studies which examine both knowledge and attitude, only the study by Dormandy et al. (2002) used a theoretical framework for this, solely in relation to serum screening. However, this study was descriptive in design and used only the attitude component of the TPB. Michie (2004) states that "there are three cognitive determinants of screening uptake that may be involved in making informed choices: attitude towards undergoing the test, perceived attitudes of others and perceived control over having the test". These form the remaining components of the TPB and therefore should merit assessment.

Aims

The current study aims to overcome some of these difficulties by;

- Providing a clear overview of the service context and type of screen offered.
- Using a questionnaire to assess whether a) women are informed and b) whether they make informed choices.
- Constructing the questionnaire using clear frameworks of the TPB and RCOG guidelines on awareness.
- Assessing all aspects of both frameworks, not merely selecting components.
- Taking demographic factors into account.

However, the overall aim of the study is to examine whether women are making informed choices, in a context where they are provided with a high level of information about a

relatively new form of screening. It is vital that the results have clinical utility and are disseminated to relevant hospital staff in the hope that they may inform everyday practice.

Research Question

Are women making 'informed choices' with regard to Combined Ultrasound & Biochemical (CUB) screening in the first trimester of pregnancy?

A high level of evidence-based information is routinely provided to women at the Queen Mother's Maternity, hence it is expected that they will be relatively well informed. As studies have found that offering screening at the first appointment promotes more informed choices, it is presumed that the current study will support this finding.

Hence, the overarching hypothesis is that women will make informed choices with regard to CUB screening. This will be determined by the support of two sub-hypotheses;
Secondary hypothesis 1 - Women will be well informed about CUB screening.
Secondary hypothesis 2 - Women's attitudes will be the most important factor in determining whether they intend to have CUB screening.

However, it is also hypothesised that **Secondary hypothesis 1** will be impacted by demographic factors, namely; parity; maternal age; socio-economic status and ethnicity

Design

This will be a prospective non-experimental study of women after they have been offered the screening test, but before the opportunity for testing.

Secondary hypothesis 1 will be supported by women scoring above a cut-off on a measure of awareness based on the RCOG guidelines.

Secondary hypothesis 2 will be supported by a greater association between behavioural intention (intending or not intending to have screening) and **attitude**, than subjective norm or perceived behavioural control components of the TPB.

It is hypothesised that **Secondary hypothesis 1** will be impacted by demographic factors in that;

- There will be a positive relationship between knowledge and each of; parity; maternal age and socio-economic category (as judged by car ownership).
- There will be a positive relationship between knowledge and ethnicity in that women from ethnic minority groups will demonstrate lower knowledge levels.

Sample

All women attending antenatal screening at the Queen Mother's Maternity hospital and satellite clinics within the time frame of the study. It is hoped that the only exclusions will be those without sufficient English to complete a questionnaire.

Measures

The main tool will be a questionnaire structured using a combination of demographic factors (appendix 3.5), the TPB (appendix 3.5) and the RCOG guidelines of awareness (appendix 3.6).

Francis et al. (2004) conducted a systematic review of 832 studies based on the Theory of Planned Behaviour and used this to provide guidance as to which questionnaire designs

fostered greatest reliability and validity. Using these guidelines, a questionnaire has been constructed to assess the following;

- Behavioural intention – whether or not they intend to have screening.
- Attitude towards screening – positive and negative evaluations of screening, and beliefs about the potential outcomes.
- Subjective norm – perceived social pressure to undergo screening and whether the person is motivated to respond to such.
- Perceived behavioural control – the person's belief in their ability to attend screening. This includes internal factors e.g. how informed they feel and external factors e.g. obstacles to attending such as finding it difficult to get time away from work.

However, it is recommended that a combination of direct and indirect measures be used to ensure validity (Francis et al., 2004). Hence it is the intention to give semi-structured pilot questionnaires to approximately 25 individuals to obtain indirect measures in the form of commonly held beliefs in relation to each TPB construct. These beliefs will then be used to inform questionnaire design. Women will be asked to evaluate each belief to determine its importance to them.

Women will be asked to respond using 7 point rating scales. For items related to attitude and perceived behavioural control, scales will be unidirectional (1-7) for direct measures and indirect beliefs and bi-directional for evaluations of beliefs (-3 to +3). For items related to subjective norm, scales will be bi-directional for direct measures and indirect beliefs and unidirectional for evaluations of beliefs (as advised by Francis et al., 2004).

For direct measures, the mean of the items will be calculated to give a score for each TPB component. For indirect measures, each belief score will be weighted by multiplying it by its corresponding evaluation score, then summed to give a score for each TPB component. In terms of assessing women's knowledge, the RCOG aspect of the questionnaire is yet to be constructed as it is hoped that this will be assisted by clinicians at the Queen Mother's. This will take the form of multiple choice questions related to each area of awareness. It is intended that one overall score will be calculated, with high scores reflecting better knowledge and good/poor knowledge defined by the midpoint of the scale.

Recruitment & Procedure

Women are sent a letter 3 weeks prior to their first appointment, with the information pack related to screening and other aspects of their antenatal care. It is intended that the pilot questionnaires will be sent to all women being offered screening appointments within a three-day period (or until 25 questionnaires are returned). The questionnaire will be preceded by a separate information sheet, outlining the purpose of the study. It is hoped that this will allow women time to consider whether to participate. Once the final questionnaire is constructed, distribution will occur in the same way as for the pilot, though over a longer time frame.

It is intended that women will have the opportunity to return the questionnaire in a sealed envelope when attending their appointment. This will be anonymous as women will not be asked to provide any identifiers on the questionnaire. Posters/leaflets will also be placed in the reception areas and copies given to receptionists, should anyone wish to complete a questionnaire just before their scan.

Time Frame

It is expected that the data will be collected over a period of 2 months. Since there are around 400 women seen at the hospital per month, this should allow for a substantial potential sample size.

Power Calculations

There are no studies which are directly comparable. Michie (2004) performed a multiple sequential regression of TPB components on intention to undergo screening, and found attitude to be the strongest predictor with a beta value of 0.467 accounting for an R^2 of 0.71 ($p< 0.001$). To replicate this finding an N of 55 would be required. If potential to achieve an R^2 of 0.8 was desired, an N of 64 would be needed.

Analyses

Secondary hypothesis 1, will involve a simple calculation percentage of women scoring above a mid-point cut-off on the RCOG awareness elements of the questionnaire. Within this, percentage of correct responses for each question will be calculated to determine any particular areas of weakness across the sample. Demographic influences will be examined by performing correlations between each one and raw knowledge score.

Secondary hypothesis 2 will be analysed using multiple regression analyses, unless there is a significant skew in the data necessitating use of non-parametric measures. Direct and indirect items must be handled separately. For direct items, item analysis will be conducted to ensure there is acceptable internal consistency. Then composite scores for each component of the TPB will be calculated (as outlined in the design section). To control for/examine the effects of the demographic variables, a hierarchical regression analysis

could be conducted using behavioural intention as the dependent variable and demographic factors as predictors at the first level, then the three other TPB components at the second.

To determine validity of the indirect items, bivariate correlations between direct and indirect scores for each TPB component could be carried out. Weighted indirect items will be summed to give a composite score for each TPB component. Then a series of multiple regression analyses can be conducted using the directly measured score for each component as the dependent variable and the weighted indirect score as the independent variable.

If any component of the TPB appears significantly more predictive of variation in behavioural intention, it may be possible to examine which beliefs contribute most to this by performing a median split on intention (e.g. low intenders versus high intenders) and performing t-tests with beliefs.

Ethical Considerations

It could be suggested that the questionnaire may dissuade individuals from undergoing antenatal screening/testing. However, the existing literature suggests that this is not likely as long as the questionnaires provide no information outwith that routinely given (Thornton et al., 1995). There is evidence to suggest that the use of questionnaires promotes informed choice, as it gives women the opportunity to reflect upon their existing knowledge and values (Wroe & Salkovskis, 1999).

Another ethical consideration is that asking women their views on screening may promote pre-screen anxiety. Again, the literature suggests that anxiety is elevated pre-screen in any case and is not affected by implementation of questionnaires (Marteau, 1988).

Finally, an important issue is to consider the possibility that a knowledge gap in an individual is identified. Is there an ethical obligation to fill this in some way? Although anonymisation will be used, it is recognised this does not absolve a researcher of their ethical duties (National Childbirth Trust, 1997). This issue cannot be resolved in the short-term hence it will be important that the study remains focused on its target of liaising closely with clinical staff to maximise the utility of the data. It is the intention that written evidence of areas of knowledge deficit, should they exist, be disseminated as quickly as possible, alongside some recommendations as to what additional information may be helpful.

Possible practical issues & costing

Permission may have to be gained to construct a questionnaire based on the TPB. There is also a practical issue of ensuring that reception staff collect completed questionnaires. Finally, there may be a cost implication in terms of the production of the questionnaire and provision of return envelopes.

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Chapter 4

Major Research Project

"Are women making 'informed choices' with regard to Combined Ultrasound & Biochemical (CUB) screening in the first trimester of pregnancy?"

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Summary

Background: Previous studies report that women fail to make informed choices with regard to antenatal screening, due to deficits in knowledge. However, current definitions dictate that informed choice occurs not merely as a result of sufficient knowledge, but by acting in line with one's attitudes despite perceived social pressure (Dormandy et al., 2002).

Objective: To investigate whether women are making informed choices with regard to Combined Ultrasound & Biochemical screening, using more substantial criteria.

Design: Prospective non-experimental.

Setting: The Queen Mother's Maternity Hospital in Glasgow.

Sample: 63 women due attend their first antenatal appointment.

Outcome measures: responses to a questionnaire constructed for the study.

Methods: A multidimensional questionnaire measure encompassing demographic factors, areas of knowledge recommended by The Royal College of Obstetricians and Gynaecologists (RCOG, 1993) and the Theory of Planned Behaviour (TPB; Ajzen, 1985).

Results: Women appeared to be well informed, though there were some worrying misconceptions. Women appeared to intend to act in line with their attitudes, although small numbers of women planning to refuse screening limited findings. Attitude was the strongest predictor of behavioural intention.

Conclusions: There appears to be moderate support for the hypothesis that women would make 'informed choices', though this is limited by a number of factors which require further investigation.

Keywords: Pregnancy; antenatal; ultrasound; biochemical; screening; knowledge; Down's Syndrome; informed choice; consent; decision-making; Theory of Planned Behaviour.

Introduction

The Queen Mother's Maternity Hospital in Glasgow offers a relatively new form of screening in the first trimester of pregnancy; Combined Ultrasound and Biochemical (CUB) screening. This has the capacity to identify those at increased risk of Down's syndrome and Trisomy 18/13 (Stenhouse et al., 2004). It involves both a blood serum test and a measure of nuchal translucency of the fetus using ultrasound. The ultrasound can also visually identify non-continuing pregnancies, severe neural tube and abdominal wall defects. CUBs takes place at 11-14 weeks, allowing women access to options unavailable at the standard 16-18 weeks e.g. surgical termination under general anaesthetic, should subsequent diagnostic tests provide more conclusive results (MIDIRS, 2005).

Despite the potential benefits, the decision to undergo screening should be carefully considered, as studies have suggested that some women regret having screening, due to receipt of high risk results (Sandelowski, 1994). There is also the potential for 'false negatives/positives'which have been found to perpetuate psychological maladjustment in parents of infants with Down's syndrome (Hall et al., 2000) or cause persisting parental anxiety (Oakley, 1997). There is also a paucity of research into the safety of the ultrasound aspect of the screen, which is attributed to women's unwillingness to become part of a 'no ultrasound' control group (Frye, 1997).

In the present context, Dormandy et al. (2002) reported that when "options are clearly presented, relevant information is given and decisions to undergo or to decline a screening test reflect the attitudes of those offered the test" this constitutes an 'informed choice'. There has been increased focus on informed decision-making since the publication of the Patient's Charter (DOH, 1991). Indeed, a publication by the General Medical Council stated that it is imperative that ultrasound screening be the result of an informed choice (GMC, 1999). In terms of screening in general, the United Kingdom National

Screening Committee recently urged for a changed approach to information giving to promote more informed choices (UKNC, 2004).

However, there have been no studies conducted to examine whether women are informed with regards to CUB screening during the first trimester of pregnancy in particular. A recent review of 64 studies involving direct data from pregnant women, identified five studies involving screening at the 14th week of pregnancy (Bricker et al., 2000). Though two looked at how knowledgeable women were in terms of both ultrasound *and* serum screening, neither looked at these when used in combination. In terms of women's knowledge in other screening contexts, Marteau et al. (1988) developed the 'Multidimensional Measure of Informed Choice (MMIC)' to measure women's knowledge of serum screening and amniocentesis. Their results suggested that women were poorly informed, particularly younger women of lower parity. Women of lower educational levels (Santalahti et al., 1998) and from ethnic minorities (Dormandy et al., 2005) have also been found to be significantly less well informed. Though Smith et al. (1994) found that women were highly informed about *procedural* aspects of serum screening for Down's syndrome, they reported that women had very little knowledge of other factors e.g. the meaning of a positive result, their options following diagnostic testing. Worryingly, Green et al. (1993) found that women in their sample remained ill informed even after undergoing a screening procedure.

One difficulty with the literature thus far, is that the information women are given in relation to screening (if any) is not discussed. Goel et al. (1996) conducted a multi-centre study of women being offered serum screening and found that those given written information were better informed. Hence it is important to examine studies which actively attempt to moderate women's knowledge by provision of information. Several studies have

found it possible to improve women's understanding of serum screening (Faden et al., 1985) and ultrasound (Oliver et al., 1996) relative to controls, using an information booklet. Despite some negative content, women valued the information and uptake remained the same. Indeed, adding extra information does not require a high technology approach, as Graham et al. (2000) showed that using touch-screen computers conferred no advantage over well-prepared information leaflets.

It is important to point out that misinformation does not necessarily equate to lower uptake (Eurenius, 1997). The author reported a high uptake rate despite women being relatively ill informed.

Some of the aforementioned studies would consider their results evidence that women do not make informed choices, as they frequently lack knowledge deemed essential in making a decision. However, when we consider the previous definition of 'informed choice' (Dormandy et al., 2002), we would conclude that having knowledge is insufficient, as attitudes must also be in line with the decision and supersede (perceived) pressure from others. There are very few studies that look specifically at attitudes in the context of informed choice in antenatal care. Dormandy et al. (2002) looked at women's decisions to have serum screening using the MMIC (Marteau et al., 1988), the attitude component of the Theory of Planned Behaviour (TPB; Ajzen, 1985 – see appendix 3.3) and a questionnaire based on eight areas of knowledge as recommended by the Royal College of Obstetricians and Gynaecologists (RCOG, 1993 – see appendix 3.4). The study compared hospitals offering screens at first appointment to those requiring an extra visit and found that women made relatively informed choices, more so if the screen was available at the time. Though there are numerous models within health psychology which may be relevant to decision making, the TPB appears to have demonstrated greatest utility (Armitage & Connor, 2001). The TPB posits that people form intentions with regard to carrying out a

particular behaviour, which are predicted by their attitude towards that behaviour, the influence of the attitudes of significant others (subjective norm) and their perceived control over the decision. The TPB has been found to predict screening behaviour in various contexts including breast cancer (Rutter, 2000), cervical cancer (Sheeran & Orbell, 2000) and colon cancer (Braithwaite et al., 2002). Michie et al. (2004) also examined informed decision-making using the TPB and found that more informed decisions were made within a routine screening context. However, as this study failed to examine knowledge it is limited in terms of its applicability to the current context. Berne-Fromell (1984) carried out a study of women declining serum screening for spina bifida in Norway, and found that though uptake rates were lower than in many studies, women's decisions to decline were more in line with their attitudes. However, the sample demonstrated unusually high levels of education.

Though studies in this area generally utilise the TPB as a framework, several other models have been proposed to evaluate individual's beliefs about their wellbeing/illness and their relationship to health behaviours. These include Attribution Theory (Kelley, 1967), Health Locus of Control (Wallston & Wallston, 1982), the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982), the Health Belief Model (Rosenstock, 1966) Protection Motivation Theory (Rogers, 1975), the Health Action Process Approach (Schwarzer, 1992) and the Self-regulatory Model of Illness Behaviour (Leventhal et al. 1980). However, all of the aforementioned models have been subject to criticism and most fail to explicitly address the concept of attitude. Utilising the definition of informed choice provided by Dormandy et al. (2002), it was considered that the TPB would be the most appropriate model, due to the inclusion of attitude as a predictor of behavioural intention. Several models of cognition commonly used in screening contexts (e.g. the Health Belief Model; Rosenstock, 1966) were felt to be less

appropriate due to the fact that pregnancy is not generally considered as an illness or a risk to health in the Western population.

The TPB itself has been subject to criticism. There have been a number of studies suggesting that the end point of the model, 'behavioural intention', is only tenuously linked to actual behaviour (Sutton, 1998). Indeed, several theorists have attempted to bridge the suggested gap between behavioural intention and behaviour. Gollwitzer et al. (1993) suggests the utilisation of 'implementation intentions', hypothesising that encouraging people to specify a time/date/place where they will adopt a new behaviour, strengthens the link between intention and actual behaviour change. However, inherent in this theory is the concept that individuals maintain a sense of control by determining when they will change. This is not applicable to the current context, where the place and time at which a new health behaviour will be adopted, is largely determined by the antenatal clinic. However, the utility of the TPB in predicting actual behaviour is not so important in the current context, as refusal of CUB screening is known to be a rare occurrence in practice.

It appears that the relationship between attitude and behaviour is complex and may be contextually dependent. Perhaps some of the difficulties in producing a model of their relationship, could be attributed to difficulties in operationalising the concept of 'attitude' in itself. Definitions of what constitutes an attitude appear to depend upon the theoretical stance adopted. In utilising the TPB as a framework and a review paper by Francis et al. (2004) as guidance in questionnaire design, the current study considers that attitude consists of an individual's beliefs as to the possible outcomes of engaging in a behaviour and their evaluations of these outcomes. It also considers that attitudes are impacted by the perceived attitudes of significant others (subjective norm) and an individual's sense of control over the behaviour in question (perceived behavioural control).

Previous studies have utilised general questions with polarised endpoints (Beneficial-Harmful, Important-Unimportant, Pleasant-Unpleasant) to assess attitude (Dormandy et al., 2002). However, the majority fail to utilise indirect measures based on beliefs as to the advantages/disadvantages of adopting a new health behaviour and evaluations of such. These studies, therefore, do not allow for the fact that individuals may simultaneously hold both positive and negative beliefs regarding different aspects of the same behaviour (Francis et al. 2004). The current study planned to address this difficulty by utilising both direct questions and indirect measures of beliefs extracted from a relevant sample and combining the two to provide an overall composite measure of attitude.

In addition to the difficulties in selecting an appropriate theoretical framework (Green et al., 2004), many of the aforementioned studies into antenatal screening fail to give contextual information e.g. why/when/where procedures carried out. This is important in terms of analysis as we need to know why a screen was carried out before we can assess knowledge. Finally, despite claiming to be investigating levels of informed choice, few studies look beyond knowledge to more attitudinal components of this. Of the three studies which examined both knowledge and attitude, only the study by Dormandy et al. (2002) used a theoretical framework for this, solely in relation to serum screening. However, this study was descriptive in design and used only the attitude component of the TPB. Michie (2004) states that "there are three cognitive determinants of screening uptake that may be involved in making informed choices: attitude towards undergoing the test, perceived attitudes of others and perceived control over having the test". These form the remaining components of the TPB and therefore should merit assessment.

Aims

The current study aims to overcome some of these difficulties by;

1. Providing a clear overview of the service context and type of screen offered.
2. Using a questionnaire to assess whether a) women are informed and b) whether they make informed choices.
3. Constructing the questionnaire using clear frameworks of the TPB and RCOG guidelines on knowledge.
4. Assessing all aspects of the TPB, not merely selecting components.
5. Taking demographic factors into account.

However, the overall aim of the study is to examine whether women are making informed choices, in a context where they are provided with a high level of information about a relatively new form of screening. It is hoped that the results will have clinical utility and are disseminated to relevant hospital staff in the hope that they may inform everyday practice.

Hypotheses

1. Women will be well-informed with regard to CUB screening, in that the majority will score above a cut-off on a measure of knowledge based on the RCOG guidelines. This is founded upon previous research suggesting that a providing high level of evidence-based information, as is the case at the Queen Mother's Maternity, promotes better knowledge of screening (Goel et al., 1996).

2. Demographic factors will have an impact upon knowledge in that younger (Marteau et al., 1988); primigravid (Marteau et al., 1988) women of lower educational levels (Santalahti et al., 1998) or from ethnic minorities (Dormandy et al., 2005) will be less well informed.

3. The women receiving a home visit by a Community Midwife prior to their appointment, will be better informed than others, having had an opportunity to discuss screening prior to completing the questionnaire.

4. Women's attitudes will be in line with their behavioural intention in that the majority of women with positive attitudes will intend to have screening, those with negative attitudes will intend not to have screening and those with neutral attitudes will be undecided (based upon the research of Berne-Fromell, 1984).

5. Women's attitudes will be the most important factor in determining behavioural intention in that for the majority of women, there will be a stronger relationship between attitude and behavioural intention than perceived behavioural control or subjective norm components of the TPB (based upon the research of Marteau et al., 1988).

6. Women will make 'informed choices', as determined by support for hypotheses 1 and 4 & 5 above.

Method:

Design:

The study is a prospective non-experimental study of women after they have been sent information asking them to consider whether to opt for the screening test (see appendix 4.2), but before the opportunity for testing.

Participants:

A power calculation was based on a study by Michie et al. (2004), who performed a multiple sequential regression of TPB components on intention to undergo screening. They found attitude to be the strongest predictor, with a beta value of 0.467 accounting for an R^2 of 0.71 ($p < 0.001$). The current study hoped to achieve an R^2 of 0.8, which would therefore require an N of 64.

Questionnaire packs were sent to a convenience sample of 400 women from the antenatal clinic list of the Queen Mother's Maternity Hospital in Glasgow, over a five-week period (guided by the time taken by the clinic to distribute information). All women were said to be in the first trimester of pregnancy. 63 returned completed questionnaires (15.75% response rate). Due to confidentiality the researcher did not have access to the patient database, hence no demographic data are available for non-responders. Inclusion criteria stipulated that women must have sufficient English to complete the questionnaire. There were no formal exclusion criteria.

Materials:

Demographic characteristics

The questionnaire also asked participants to provide information regarding their; age, ethnicity, educational status, education, socio-economic status (car ownership), employment status, parity, previous experience of Down's Syndrome screening and the antenatal clinic they would be attending. Women were also asked if they had received a visit from a community midwife.

Knowledge

A self-report scale was developed to measure knowledge of the CUB screening test. Five multiple-choice items were derived from some of the key areas of awareness as

identified by RCOG (1993) namely; procedural knowledge, the meaning of a 'high chance' screening result, the meaning of a 'low chance' screening result, the options following a 'high chance' screening result, the options following a positive diagnostic test. The possible response endings to questions were derived from the booklets routinely sent to all pregnant women on the antenatal clinic list. Some questions had more than one correct answer, in these cases counterbalancing with incorrect answers was applied. Negative scoring was utilised, resulting in one overall score being calculated with a range of 0-8, with high scores reflecting better knowledge and good/poor knowledge defined by cut-off point of 5. Existing literature (Marteau et al., 1988) advocates usage of a midpoint cut-off, though this was not possible on a scale of 0-8. The five-item scale had a standardised alpha co-efficient of reliability in this sample of 0.57. Two further questions were included to determine whether women had read and felt they understood the information booklets provided to them by the antenatal clinic.

TPB components

Francis et al. (2004) conducted a systematic review of 832 studies based on the Theory of Planned Behaviour and used this to provide guidance as to which questionnaire designs fostered greatest reliability and validity. They recommended that a combination of direct and indirect measures be used to ensure validity. Hence a semi-structured version of the questionnaire (see appendix 4.4) was sent to 50 women on the antenatal clinic list to obtain indirect measures, in the form of most commonly held beliefs in relation to each TPB construct (excluding behavioural intention). 15 women returned completed questionnaires. These beliefs were then divided into common themes and placed in order of frequency. 75% of the most frequently reported beliefs for each construct were used to form indirect questions. The final questionnaire was piloted for readability with a

convenience sample of 5 non-pregnant women and amended as appropriate (see appendix 4.5 for full questionnaire).

During the main study, women were asked to respond using 7 point rating scales from 'strongly disagree' to 'strongly agree'. Women were then asked to evaluate each belief to determine its importance to them on 7 point scales using either; 'strongly disagree'-'strongly agree'; 'extremely undesirable'-'extremely desirable'; "less likely"-"more likely" where appropriate. For direct measures, the mean of the items was calculated to give a score for each TPB component. For indirect measures, each belief score was weighted by multiplying it by its corresponding evaluation score, then summed to give a score for each TPB component.

Behavioural intention

Behavioural intention was measured using three direct questions; "I expect to have Down's Syndrome screening during this pregnancy", "I want to have Down's Syndrome screening during this pregnancy" and "I intend to have Down's Syndrome screening during this pregnancy". When the mean of the three items was taken, scores ranged from one to seven. This scale had a strong alpha coefficient of reliability of 0.98.

Attitude towards screening

Attitude towards CUB screening was measured firstly by one direct question "Having Down's Syndrome screening will be… Bad for me – Good for me" on a 7-point scale. Though use of several direct items may have been of benefit, there were concerns as to length of the measure. In addition, Francis et al. (2004) suggested that the aforementioned question captures 'overall evaluation'.

Six indirect questions were utilised, drawing on the most commonly elicited beliefs. Three questions related to advantages of screening – screening will "give me the information I need to make decisions during my pregnancy"; "reduce my worry by reassuring me that the baby has a lower chance of having this condition"; "give me time to prepare for the possibility of having a baby with this condition". The remaining questions related to disadvantages – "I may be given a false negative result"; "I may be given a false positive result"; "the result I am given may lead me to decide to have diagnostic tests, which carry a risk of miscarriage". The responses were weighted by their evaluations and summed to give a composite score, ranging from -21 to +21. Internal consistency of indirect measures were not examined as Francis et al. (2004) pointed out that women could hold both positive and negative beliefs regarding different aspects of the same behaviour e.g. they may feel screening would cause them to worry, but that it would also provide them with vital information regarding their pregnancy.

Subjective norm (perceived social pressure)

This was initially measured using two direct questions – "I feel under pressure from others to have Down's Syndrome screening", "Most people who are important to me think that I should have Down's Syndrome screening". When the mean of the two items was taken, scores ranged from one to seven. This scale had an alpha coefficient of reliability of 0.52, which was lower than expected.

Four indirect questions were utilised, drawing on the most commonly elicited beliefs as to which groups of people influence women's screening decisions. Women were asked whether they thought that their partner, health professionals, family and friends believed that they should undergo screening. When the responses were weighted by their evaluations and summed to give a composite, scores ranged from -21 to +21.

Perceived behavioural control

Perceived behavioural control was measured by three direct questions – "It would be difficult for me to have Down's Syndrome screening", "I am confident that I would be able to have Down's Syndrome screening", "It is my decision whether or not I have Down's Syndrome screening". When the mean of the three items was taken, scores ranged from one to seven. This scale had an alpha coefficient of reliability of 0.63, however, when the first direct item was removed this increased to 0.92. However, it was not appropriate to exclude the item due to lack of comparative studies to provide evidence of construct validity and the possibility that PBC may involve more than one dimension.

Four indirect questions were utilised, two of which involved possible barriers to screening – "Having to take time off work makes it more difficult for me to have Down's Syndrome screening", "The distance I live from the antenatal clinic makes it more difficult for me to have Down's Syndrome screening". Two items addressed possible facilitators to screening – "Having information leaflets makes it easier for me to have Down's Syndrome screening", "Knowing that Down's Syndrome screening is available to everyone makes it easier for me to have Down's Syndrome screening". When the responses were weighted by their evaluations and summed to give a composite, scores ranged from -21 to +21.

All measures were found to take approximately 20-25 minutes to complete in total.

Procedure:

Women due to attend antenatal clinics were routinely sent their appointment 2-3 weeks in advance, together with the information pack related to screening and other aspects of their antenatal care. Clinic reception staff agreed to send questionnaires alongside this pack. The questionnaire was preceded by a separate information sheet and

consent form (see appendix 4.3). Women were also provided with freepost envelopes to return the questionnaires. Women were not asked to provide identifiers. Appointments were sent from the main clinic, even if women were due attend one of four satellite clinics, hence the procedure remained the same.

Statistical Analysis

Parametric data: Knowledge will be assessed by calculation of the percentage of women scoring above a cut-off. Demographic influences will be examined by performing Pearson's correlations and One-way ANOVA. Whether women receiving home visits will be better informed will be examined by performing t-tests. Relationships between TPB components and intention will be examined using Pearson's correlations and multiple regression analyses. Depending on sample size, hierarchical regression analysis will be conducted to control for demographic factors.

Nonparametric data: Pearson's correlations will be replaced with Spearman's rank. Mann-Whitney U and Kruskal-Wallis tests will be performed as alternatives to t-tests and One-way ANOVA.

RESULTS

Demographic characteristics

A one-sample Kolmogorov-Smirnov test of goodness-of-fit provided support for the hypothesis that the sample was derived from a normal population in terms of age: D = 0.131; exact p = 0.208 (two-tailed). The mean age was 30.76 (SD = 6.05; range 17-41) years. Women taking part tended to be married (50.8%), university educated (63.5%), employed (74.6%) and were car owners (71.4%). Three participants considered themselves as being within an ethnic minority group. The majority reported that this was not their first

pregnancy (58.7%). Most were due to attend the main clinic at the Queen Mother's Maternity Hospital in Glasgow (76.2%). Seven had been previously visited by a Community Midwife. The demographic data are summarised in table 1.

INSERT TABLE 1 ABOUT HERE

Knowledge

62 women reported that they had read and understood the information sent. The mean knowledge score was 5.83 (SD = 1.63) and the median score 6 (interquartile range = 2). 52 (82.5%) scored 5 or more. A one sample Kolmogorov-Smirnov test suggested that the knowledge scores were skewed above the mean (D= 0.177; exact p = 0.034 two-tailed) as illustrated in table 2 below.

INSERT TABLE 2 ABOUT HERE

A high proportion obtained maximum scores in terms of the meaning of a 'high chance' (95.2%) and 'low chance' (95.2%) result. However, 25 women believed that they could have a termination following screening and 14 viewed amniocentesis as a screen rather than a diagnostic. 24 women failed to identify that screening would involve an ultrasound scan. 20 women also failed to select that, following a 'high chance' result from screening, they could continue with the pregnancy. Errors are summarised in table 3 below.

INSERT TABLE 3 ABOUT HERE

As non-parametric equivalents of ANOVA, Kruskal-Wallis k-sample tests suggested knowledge scores were found to be significantly affected by relationship status (χ^2 (2) = 8.258; $p<0.05$), education (χ^2 (2) = 8.167; $p<0.05$), employment status (χ^2 (1) =

5.360; $p<0.05$) and previous experience of screening (χ^2 (1) = 4.162; $p<0.05$). A Mann Whitney U test demonstrated no significant differences between women who had or had not received a midwife visit (U = 158.0; exact p = 0.418, two tailed), in terms of knowledge. See table 4 below for demographic influences.

INSERT TABLE 4 ABOUT HERE

Intention

The mean score for intention was 5.56 (SD = 2.02) and the median 6.67 (interquartile range = 2). A Kolmogorov-Smirnov test suggested that the intention scores were highly skewed above the mean (D= 0.254; exact p = 0.001, two-tailed). Kruskal-Wallis k-sample tests suggested that previous experience of screening was significantly related to intention to have CUB screening (χ2 (1) = 5.002; $p<0.05$). A Spearman's Rho failed to identify a significant relationship between intention and knowledge (r (59) = 0.241, p = 0.061), see table 5 below.

INSERT TABLE 5 ABOUT HERE

Attitude

Direct:

43 women (70.5%) ascribed a score of between 5 and 7 to their attitude towards having CUB screening, indicating a largely positive attitude, as illustrated in table 6 below. The mean score was 5.46 (SD = 1.95) and the median 6 (interquartile range = 3). A Kolmogorov-Smirnov test of suggested scores were significantly skewed above the mean (D= 0.254; exact p = 0.001, two-tailed). A Spearman's Rho found attitude to be significantly positively correlated with intention (r (58) = 0.721, p = 0.000).

INSERT TABLE 6 ABOUT HERE

Indirect:

Based upon the indirect questions, the majority of the women rated their attitude towards screening as positive (52.5%). However, a greater proportion of women rated their attitude as negative (32.9%) than when direct measures of attitude were used. A Kolmogorov-Smirnov test suggested that the intention scores were normally distributed (D= 0.120; exact p = 0.316 two-tailed).

A Spearman's rho revealed that direct and indirect measures were highly correlated overall, however three questions involving possible disadvantages of screening were not correlated with the direct measures. Attitude was found to be significantly positively correlated with intention (r (58) = 0.470, p = 0.000). Upon closer inspection, significant correlations were found only between intention and three items relating to the advantages of screening.

Subjective Norm

Direct:

The majority of women (72.1%) ascribed a score of between 1 and 3, indicating that most experienced pressure to refuse screening. The mean score was 2.7 (SD = 1.65) and the median 2.5 (interquartile range = 3). A Kolmogorov-Smirnov suggested that subjective norm scores were significantly skewed below the mean (D= 0.194; exact p = 0.017 two-tailed). Kruskal-Wallis k sample tests suggested no influence of demographic factors or whether women had received a midwife, in terms of perceived social pressure.

Indirect:

Using indirect measures, a greater proportion of women (43.1%) reported experiencing pressure to have screening. 24 (41.4%) women reported experiencing pressure to refuse screening. A Kolmogorov-Smirnov test revealed that the data were normally distributed ($D = 0.105$, exact $p = 0.507$, two tailed).

Spearman's rho results indicated that indirect measures were highly correlated with direct measures ($r(55) = 0.719$, $p < 0.001$). There was a significant positive correlation between indirect subjective norm score and intention ($r(55) = 0.391$, $p = 0.003$). Each of the individual indirect questions were found to be correlated with intention, though this relationship was weaker when the question related to the views of health professionals ($r(59) = 0.295$, $p = 0.021$).

Perceived Behavioural Control

Direct:

The mean score was 6.23 (SD = 1.28) and the median 7 (interquartile range = 1.17). 54 women (88.5%) provided a score of between 5 and 7, indicating a sense of control over their decision. A one-sample Kolmogorov-Smirnov revealed that the data were significantly skewed above the mean ($D = 0.321$, exact $p = 0.000$, two tailed). Kruskal-Wallis k sample tests demonstrated that demographic factors were not related to women's sense of perceived behavioural control.

Indirect:

Using indirect measures women continued to report positive scores, indicating a sense of control over their screening decisions (78%). A Kolmogorov-Smirnov test

demonstrated that the scores were normally distributed ($D = 0.137$, $p = 0.309$) around the mean of 5.69 (SD = 4.39).

Though the difference approached significance, Spearman's rho correlations revealed that indirect scores were not correlated with direct scores ($r(48) = 0.27$, $p = 0.058$). Upon closer inspection, questions involving potential barriers to screening were not correlated with direct measures of PBC, but those involving factors intended to ease access to screening were. There was a significant positive relationship between indirectly measured PBC and intention ($r(48) = 0.660$, $p < 0.001$), though in terms of individual questions this relationship was only significant for factors improving access.

Influence of TPB components on intention

Focusing upon direct measures, Spearman's rho correlations revealed that attitude, subjective norm and PBC were all significantly positively correlated with intention. The strongest relationship was seen between attitude and intention ($r(58) = 0.721$, $p < 0.001$). Using indirect measures, all components were again significantly positively correlated with intention. However, perceived behavioural control was found to have the strongest relationship with intention ($r(48) = 0.660$, $p = <0.01$). It should be noted that PBC scores were based upon a subset of the sample who were employed, as one of the questions related to time away from work as a potential barrier. Correlations between components and intention are summarised in tables 7-9 below.

INSERT TABLES 7, 8 & 9 ABOUT HERE

Due to the presence of non-parametric data, the TPB components were converted into ranks before regression analyses of TPB components on intention were conducted.

The following independent variables were entered: attitude direct; attitude indirect; subjective norm direct; subjective norm indirect; PBC direct and PBC indirect. Using the enter method, a significant model emerged ($F_{6,39} = 14.17$, $p < 0.001$. Adjusted $R^2 = 0.637$). Attitude direct ($\beta = 0.346$, $p = 0.005$) and PBC indirect ($\beta = 0.308$, $p = 0.011$) emerged as significant predictors of intention. Attitude indirect ($\beta = 0.22$, $p = 0.057$), subjective norm direct ($\beta = 0.134$, $p = 0.29$), subjective norm indirect ($\beta = 0.131$, $p = 0.297$) and PBC direct ($\beta = -0.011$, $p = 0.909$) failed to emerge as significant predictors of intention (corresponding t-values provided in table 10). Due to small sample size, particularly with regard to PBC, a hierarchical regression including demographic factors was not utilised due to potential model collapse. However, it was felt that demographic influences would be sufficiently accounted for by earlier analyses. Regression analyses are summarised in table 10 below.

INSERT TABLE 10 ABOUT HERE

A regression analysis of TPB components on intention, amongst the group of women with 'good knowledge' (scoring 5 or more), was conducted. The following independent variables were entered: attitude direct; attitude indirect; subjective norm direct; subjective norm indirect; PBC direct and PBC indirect. Using the enter method, a significant model emerged ($F_{6,35} = 14.91$, $p < 0.001$. Adjusted $R^2 = 0.671$). Significant predictor variables were PBC indirect ($\beta = 0.325$, $p = 0.005$), attitude direct ($\beta = 0.316$, $p = 0.009$) and attitude indirect ($\beta = 0.235$, $p = 0.034$). Subjective norm indirect ($\beta = 0.157$, $p = 0.204$), subjective norm direct ($\beta = 0.145$, $p = 0.239$), and PBC direct ($\beta = -0.004$, $p = 0.966$) failed to emerge as significant predictors of intention.

Discussion

Inspection of demographic data indicated that the sample of women taking part in the study could not be deemed to be representative of pregnant women as a group. The majority were married, employed, of higher socioeconomic status and had had a previous pregnancy. Most striking is the fact that 63.5% of the sample were university educated, which perhaps accounts for the high knowledge levels. This is in stark contrast to data provided during the most recent census, which suggested that only 12.9% of women aged 16-44 years in Glasgow were university educated (Census, 2001). There are, therefore, significant issues in terms of generalisability of the findings thus the results must be interpreted with great caution. This lack of representativeness could most likely be attributed to the use of self-report questionnaires. A more representative sample would perhaps have been achieved had the research taken the form of interviews prior to the antenatal appointments, however this was not permitted as management felt that it would interfere with the running of the clinics. In addition, the ethics committee dictated that asking women to complete questionnaires just prior to their appointment would not allow them sufficient time to contemplate their decision as to whether to participate.

Taking into account issues related to generalisability, limited support was found for the hypothesis that women would be well-informed with regard to CUB screening, in that the majority scored above a cut-off on a measure of knowledge based on the RCOG guidelines. This lends support to the research of Goel et al. (1996) who suggested that a providing high level of evidence-based information promotes better knowledge of screening, as the majority of the women reported reading and understanding the booklets provided.

However, these results should be interpreted with caution, as a number of common misconceptions were evident. Many women failed to identify that, if they were to receive a

high chance result from screening, they would be entitled to continue with the pregnancy as normal. Others thought that they might be able to opt for a termination following screening, though this could be accounted for by a lack of specificity in the response ending, which may have been better phrased “to have a termination without having diagnostic testing”. A substantial number of women failed to identify that ultrasound scans form a crucial part of the screening process, a worrying finding given that this aspect of screening holds equal weighting with blood testing. During liaison with clinic staff, it was reported that women occasionally consent to measurement of the nuchal fold during ultrasound then refuse the blood test. It appears that further exploration of women’s understanding of the purposes of nuchal fold measurement may be required, as is also suggested in an interesting anecdotal report of one woman’s experience of ultrasound (Venn-Treloar, 1998). The final misconceptions relate to amniocentesis, with a high proportion of women viewing this procedure as a screen rather than a diagnostic test. Again, the implication of this in terms of informed decision making should be considered. These misconceptions appear to have been masked by women’s extremely high performance on questions relating to the possible results (e.g. ‘high chance’ or ‘low chance’) of screening. In retrospect, these questions may have lacked utility as the ethics committee requested they be rephrased in such a way that incorrect responses were very unlikely. The aforementioned misconceptions are particularly striking, given the high levels of education within the sample. Paasche-Orlow et al. (2005) conducted a systematic review examining the prevalence of limited health literacy in the United States and found a strong association between low ability to process health related information and level of education. This, despite the lack of representativeness of the sample, the identification of common misconceptions is of great interest.

As the sample was considered to be a demographically poor representation of pregnant women, it is difficult to draw any conclusions as to whether the hypothesis that younger, primigravid women of lower educational levels or from ethnic minorities would be less well informed was supported. Though the performance of women of lower educational levels was found to be significantly lower (as was the performance of those who were single, unemployed and had no previous experience of screening), between-group comparisons lacked utility due to significant skews in the data.

The hypothesis that women receiving a home visit by a Community Midwife would be better informed than others failed to receive support. However, only seven women who had received a visit responded, which could be attributed to similar responder bias as aforementioned, as many of the satellite clinics are situated in more deprived areas of Glasgow.

There was support for the hypothesis that women's attitudes would be in line with their behavioural intention (Berne-Fromell, 1984) in that the majority of women with positive attitudes intended to have screening, those with negative attitudes generally intended to refuse screening and intention varied for those with neutral attitudes. However, given that only eight women expressed a negative attitude towards screening and eleven women intended to refuse screening overall, results must be interpreted with caution. Furthermore, in utilising indirect measures of attitude, questions relating to perceived advantages of screening were significantly related to intention whereas disadvantages were not. Whilst this may suggest that the advantages outweigh the disadvantages, given the misconceptions mentioned previously, it may be the case that women did not consider the possible disadvantages likely to occur.

The hypothesis that women's attitudes would be the most important factor in determining behavioural intention was generally supported, using direct measures, as there

was indeed a stronger relationship between directly measured attitude and behavioural intention than perceived behavioural control or subjective norm components of the TPB. However, when utilising indirect methods, perceived behavioural control had the strongest relationship with intention. As perceived behavioural control was measured within a much smaller group of employed women, it was felt that this should not detract from the support of the hypothesis. Indeed, when regression analyses were performed, directly measured attitude emerged as the strongest predictor of intention. However, indirectly measured attitude did not emerge as a predictor of intention. This could be attributed to the presence of questions relating to disadvantages of screening, as aforementioned. In retrospect, perhaps the PBC question relating to employment should have been substituted with one more applicable to the whole sample, however responses to the semi-structured questionnaire dictated inclusion of items.

The final hypothesis was concerned with whether women would make 'informed choices', as determined by support for hypotheses 1 and 4 & 5 plus some additional analyses. Women did appear to be relatively informed on the whole, though there were some worrying misconceptions, as previously discussed. Women appeared to intend to act in line with their attitudes, though small number of women planning to refuse screening or holding negative attitudes limited the findings. Directly measured attitude did appear to be the most important factor in predicting behavioural intention, though indirect measurements of attitude were not found to be particularly predictive amongst the sample as a whole. However, when the regressions were repeated within a subgroup of women with 'good knowledge', direct attitude emerged as the strongest predictor and indirect attitude was also found to account for a small proportion of the variance in intention. Overall, there appears to be moderate support for the hypothesis that women would make 'informed choices', though this is limited by a number of factors.

The fact that during the brief period of this study, eleven women reported that they intended to refuse screening is interesting as clinic staff report that this is a rare occurrence in practice. Whilst this could be interpreted as evidence that having the opportunity to reflect upon their decision whilst completing the questionnaire has altered their perspective, it could also be evidence of the fact that intentions are not necessarily related to actual behaviours (Armitage & Connor, 2001).

Though difficulties with the current study in terms of specific hypotheses and representativeness have already been discussed, there are a number of more general limitations which should be highlighted. The development of the questionnaire may have benefited from further evaluation using a larger sample, particularly as there were some issues in terms of internal consistency. However, it was felt that the development of a new measure was worthwhile, as previous questionnaires failed to assess all components of the TPB. Guidelines for development of a TPB questionnaire (Francis et al., 2004) were followed as far as possible. Secondly, the questionnaire failed to examine all aspects of knowledge as outlined by RCOG (1993), focusing on five of the eight areas of awareness. Though it was the intention to address all key areas, questionnaire length was an issue. The ethics committee also requested the removal of several items in the knowledge section due to the possibility that they may cause distress (e.g. questions relating to termination and the effects of specific genetic conditions). Perhaps ethics committees should consider their decisions in such cases more carefully, given that when making an 'informed choice' women should be provided with all information – including that which would be considered distressing. Indeed, the booklet provided by the clinic reports that;

"In babies with anencephaly the skull and brain are not properly formed. These babies generally die before or very soon after they are born." (NHS Scotland, 2006).

Thus all aspects of women's knowledge, including that of potentially distressing outcomes, should be assessed in future studies. Thirdly, the study failed to assess psychological factors such as anxiety or depression, which may have impacted upon women's ability to absorb information regarding screening procedures and may alter responses to TPB components e.g. dysfunctional attitudes (Cannon et al, 1999). Again, questionnaire length was an issue. Finally, the fact that women completed the questionnaire at home meant that they may have referred to the clinic information booklet on questions relating to knowledge of screening procedures. This difficulty could have been avoided had questionnaires been completed in the clinic, though this was not possible for reasons mentioned before. Women would have had to interpret the information in the correct way to achieve a reasonable knowledge score, though their retention of such may not be adequately assessed by the current measure.

Lack of representativeness of the sample, as a product of the study methods, is undoubtedly a serious flaw within the study and limits the utility of the findings. However, a number of issues arose which may merit further investigation. The frequency of misconceptions in women's knowledge of antenatal screening procedures was unexpected, particularly in such a highly educated sample. Future research in this area may wish to focus upon the investigation of this issue using a larger, more representative sample. It may also be of interest for studies to adopt behaviour (e.g. having/refusing CUBs) as the dependent variable as opposed to intention. Finally, the fact that many women taking part in the current study were unaware that ultrasound forms part of the screening process, is of interest and would undoubtedly benefit from further examination.

Conclusions

The present exploratory study is useful in that it adds to the research in the psychology of maternity, by demonstrating that women are relatively well informed with regard to screening and make decisions based upon their attitudes and the information they have accrued. The results of this study demonstrate that women are less likely to be influenced by the opinions of others or potential barriers, when making decisions regarding screening.

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TABLE 1: Demographic characteristics of pregnant women

			All pregnant women (*n = 63*)
	n		
Age:	63	Mean (years)	30.76
		SD (years)	6.05
		Range (years)	17 - 41
			n (%)
Relationship status:	63	Single	6 (9.5)
		In a relationship	25 (39.7)
		Married	32 (50.8)
Ethnicity:	62	White	59 (95.2)
		Chinese	1 (1.6)
		Other	2 (3.2)
Education:	62	School	10 (16.1)
		College	12 (19.4)
		University	40 (64.5)
Car owner:	63	No	18 (28.6)
		Yes	45 (71.4)
Employment status:	63	Not employed	16 (25.4)
		Employed	47 (74.6)
Parity	63	Primigravid	26 (41.3)
		Multigravid	37 (58.7)
Previous DS screening:	62	No	37 (59.7)
		Yes	25 (40.3)
Clinic:	63	Main	48 (76.2)
		Satellite	15 (23.8)
Visit from midwife:	63	No	56 (88.9)
		Yes	7 (11.1)

TABLE 2: Results for individual questions on knowledge measure

			Question & possible range of scores		
		n (%)			*n (%)*
Knowledge score	1	1 (1.6)	*Question 13: What screening involves (0-2)*	0	2 (3.2)
	2	2 (3.2)		1	25 (39.7)
	3	2 (3.2)		2	36 (57.1)
	4	6 (9.5)			
	5	15 (23.8)		0	2 (3.2)
	6	11 (17.5)	*Question 14: Meaning of a 'high chance' result (0-1)*	1	61 (96.8)
	7	17 (26.9)			
	8	9 (14.3)			
Overall knowledge score:	Mean	5.83		0	3 (4.8)
	SD	1.63	*Question 15: Meaning of a 'low chance' result (0-1)*	1	60 (95.2)
	Median	6			
	Interquartile range	2			
			Question 16: Options following a 'high chance' result (0-2)	0	7 (11.1)
				1	38 (60.3)
				2	19 (28.6)
			Question 17: Options following positive amniocentesis (0-2)	0	22 (34.9)
				1	5 (7.9)
				2	36 (57.1)

TABLE 3: Most common incorrect & omitted responses on measure of knowledge

	Response	*n (%)*
Incorrect:	*If a woman was given a 'high chance' result one of her options would be to have a termination within a few days*	25 (39.7)
	A woman would be told only that her baby has a 'higher chance' of Down's syndrome following amniocentesis	14 (22.2)
	A woman would be told only that her baby has a 'lower chance' of Down's syndrome following amniocentesis	6 (9.5)
Omitted:	*Down's syndrome screening involves having an ultrasound scan*	24 (38.1)
	Following amniocentesis, a women may be told that her baby almost certainly does not have Down's syndrome	23 (36.5)
	Following a 'high chance' result, one option a woman has is to continue with the pregnancy as normal	20 (31.7)
	Following amniocentesis, a women may be told that her baby almost certainly does have Down's syndrome	16 (25.4)
	Down's syndrome screening involves giving a sample of blood	5 (7.9)

TABLE 4: Demographic influences on knowledge

		n	Median (Interquartile range)	Results of Kruskal-Wallis ($\chi 2$)	exact p-value
Age:	= 25	12	5 (4)		
	26-30	14	5.5 (3)		
	= 31	37	6 (2)	n.s.	0.204
Relationship status:	Single	6	4 (4)		
	In a relationship	25	5 (2)		
	Married	32	7 (2)	*$\chi 2$ (2) = 8.258**	0.013
Ethnicity:	White	59	6 (2)		
	Other	3	5 (0)	n.s.	0.516
	Missing data	1			
Education:	School	10	5 (2)		
	College	12	5.5 (2)		
	University	40	7 (2)	*$\chi 2$ (2) = 8.167**	0.015
	Missing data	1			
Car ownership:	No car	18	6 (3)		
	Car	45	6 (2)	n.s.	0.312
Employment status:	Not employed	16	5 (3)		
	Employed	47	6 (2)	*$\chi 2$ (1) = 5.360**	0.019
Parity:	Primigravid	26	5 (2)		
	Multigravid	37	6 (2)	n.s.	0.118
Previous experience of screening:	No	37	5 (2)		
	Yes	25	7 (2)	*$\chi 2$ (1) = 4.162**	0.041
	Missing data	1			
Visit from midwife:	No	56	6 (2)		
	Yes	7	7 (3)	n.s.	0.418

TABLE 5: Demographic influences on intention

		n (%)	Median (Interquartile range)	Results of Kruskal-Wallis ($\chi 2$)	asymptotic p-value
Intention					
Score: 1-3	(Plan to refuse screening)	11 (18)			
4	(Undecided)	2 (3.3)			
5-7	(Plan to have screening)	48 (78.7)			
	Mean	5.56			
	SD	2.02			
	Median	6.67			
	Interquartile range	2			
Age:	= 25	11	6.16 (6)		
	26-30	14	6.5 (2)		
	= 31	36	6.83 (2.75)	n.s.	0.994
	Missing data	2			
Relationship status:	Single	5	5.33 (1.33)		
	In a relationship	24	7 (1.67)		
	Married	32	6.16 (3.5)	n.s.	0.1
	Missing data	2			
Ethnicity:	White	57	7 (2.5)		
	Other	3	6.33 (0)	n.s.	0.722
	Missing data	3			
Education:	School	9	5.33 (2.5)		
	College	12	7 (2)		
	University	40	6.5 (2.67)	n.s.	0.723
	Missing data	2			
Car ownership:	No car	17	5.16 (5.25)		
	Car	44	7 (1.58)	n.s.	0.131
	Missing data	2			
Employment status:	Not employed	14	5.67 (6)		
	Employed	47	6.67 (1.67)	n.s.	0.444
	Missing data	2			
Parity:	Primigravid	25	6 (2)		
	Multigravid	36	7 (2.67)	n.s.	0.584
	Missing data	2			
Previous experience of screening:	No	36	5.67 (3)		
	Yes	25	7 (1.17)	*x2 (1) = 5.002**	0.025
	Missing data	2			

* $p<0.05$

Table 6: Frequency data for direct attitude towards and intention to have screening

	Intend to have screening?	*n (%)*
Attitude direct:		
Negative (1-3)	No	7 (87.5%)
	Unsure	0
	Yes	1 (12.5%)
Neutral (0)	No	3 (30%)
	Unsure	2 (20%)
	Yes	5 (50%)
Positive (5-7)	No	1 (2.4%)
	Unsure	1 (2.4%)
	Yes	40 (95.2%)
Subjective norm direct:		
Negative social pressure (1-3)	No	11 (25%)
	Unsure	1 (2.3%)
	Yes	32 (72.7%)
Neutral social pressure (4)	No	0
	Unsure	1 (10%)
	Yes	9 (90%)
Positive social pressure (5-7)	No	0
	Unsure	0
	Yes	6 (100%)
PBC direct:	Intention	*n* (%)
Sense of lack of control (1-3)	No	5 (83.3%)
	Unsure	0
	Yes	1 (16.7%)
Unsure (4)	No	0
	Unsure	0
	Yes	1 (100%)
Sense of control (5-7)	No	6 (11.1%)
	Unsure	2 (3.7%)
	Yes	46 (85.2%)

TABLES 7, 8 & 9 (SEE SEPARATE DOCUMENT)

TABLE 10: Regression analyses of TPB components on intention

		Adj. R^2	R^2	F (df)	Beta	t (df)	p
Simultaneous regressions:							
All TPB components: n = 46		0.637	0.686	14.17 (6,39)			
Variables entered:	Attitude direct				0.346***	2.96 (39)	0.005
	Attitude indirect				0.22	1.96 (39)	0.057
	S norm direct				0.134	1.07 (39)	0.29
	S norm indirect				0.131	1.06 (39)	0.297
	PBC direct				-0.011	-0.114 (39)	0.909
	PBC indirect				0.308*	2.68 (39)	0.011
All TPB components in those with good knowledge: n = 42		0.671	0.719	14.91 (6, 35)			
Variables entered:	Attitude direct				0.316**	2.77 (35)	0.009
	Attitude indirect				0.235*	2.21 (35)	0.034
	S norm direct				0.145	1.19 (35)	0.239
	S norm indirect				0.157	1.29 (35)	0.204
	PBC direct				-0.004	-0.043 (35)	0.966
	PBC indirect				0.325**	2.96 (35)	0.005

* $p < 0.05$ ** $p < 0.01$ *** $p < 0.001$

Chapter 5

Single Case Experimental Design Proposal (Abstract)

"Does anger 'treatment' provide any additional benefit over anger 'management' – the case of a 45-year-old female with mild learning disability and borderline personality?"

Clare McGowan, University of Glasgow, Section of Psychological Medicine, Gartnavel Royal Hospital
Dr Sarah Wilson, University of Glasgow, Section of Psychological Medicine, Gartnavel Royal Hospital

(See part two for full proposal)

Correspondence to: Clare McGowan
Section of Psychological Medicine
Division of Community Based Sciences
Academic Centre
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology.
Prepared in accordance with the requirements for submission to the British Journal of Learning Disabilities.

Abstract

Background: Anger related difficulties are said to be common in people with learning disabilities (Harris, 1993; Sigafoos et al., 1994). However, most treatments tend to adopt 'anger management' techniques, said to be "*less intensive, not driven by individual analysis and formulation*" (Novaco, 2000). There is evidence that although short-term gains can be made, there is often post-therapeutic regression (Taylor & Novaco, 2005). In contrast, 'anger treatment' approaches "*targeted at the modification of cognitive structures that maintain anger*" (Taylor & Novaco, 2005), are rarely utilised.

Objective: To determine whether 'anger management' would lead to a reduction in the anger symptomatology of a woman with a mild learning disability and whether 'anger treatment' (including stress inoculation) would lead to further improvement, in comparison to measures taken following completion of the anger management phase.

Design: An A, B_1, B_2 design would be utilised, where B_1 would be a traditional 9 session anger management phase and B_2 an 11 session anger treatment phase.

Setting: Glasgow Learning Disability Partnership, a collaborative provision involving both Social Work services and the UK National Health Service.

Participants: A 45-year-old female with mild learning disability and borderline personality.

Outcome measures: The Novaco Anger Scale (NAS; Novaco, 2003); State-Trait Anger Expression Inventory (STAXI; Spielberger, 1996); Provocation Inventory (PI; Novaco, 2003); Ward Anger Rating Scale (WARS; Novaco, 1994) plus daily recordings of verbal aggression.

Analyses: Related t-tests to compare B_1 scores with A scores and B_2 scores with A and B_1 scores (preceded by autocorrelation procedures). Should the data prove to be serially dependent, time series analyses would be performed.

Appendix 1.1

Powerpoint presentation of First Year Audit project

Slide 1:

An examination of referral characteristics to the Older Adult Psychology & Neuropsychology services in Dumfries & Galloway, as a means of providing baseline measures for forthcoming organisational change.

July 2005

Slide 2:

Proposed Organisational Change

- ***Model of service – strategy: mental health for older adults*** (Department of Psychological Services & Research, 2004*)*

  This stated that in order to provide a good level of psychology service in all tiers of older adult care, two A grade Clinical Psychologists are required in addition to 3 Clinical Psychology Trainees who will take up posts as 'Registrar Psychologists' shortly.

Slide 3:

Aims of the audit

1. To describe the characteristics of the population referred to the Older Adult Psychology service over a four year period.
2. To look specifically at patterns of General Practitioner (GP) referrals to the Older Adult service over a four year period. This involved comparison of referral rates with Older Adult list sizes for each practice.
3. To examine patterns of referrals of older adults to the Neuropsychology service

Slide 4:

Background

- ***National Service Framework for Older People*** (DOH, 2001)
- ***Priorities & Planning Framework 2003-06*** (DOH, 2003)
- ***Mental Health of Older People Report*** (National Statistics, 2003)
- ***Liaison Psychiatry and Psychology Needs Assessment Report*** (NES, 2004)
- ***Clinical Psychology Workforce Planning Report*** (NES, 2002)
- ***Future issues in population and health care*** (Carnon, 2002)

Slide 5

Methodology

- This was a retrospective audit describing 4 years of referral data to the Older Adult Psychology service, between the 1st January 2001 and 31st December 2004 (n = 447).
- All data was extracted from the 'Patient Management System' (PMS), a Microsoft Access program.
- A descriptive account of referral characteristics including referrer, geographical area, age and gender was provided. Diagnosis, as decided by clinician at end of treatment, was also given. Data pertaining to GP referrals was extracted.
- Population data used were those of the Public Health records of NHS Dumfries & Galloway (2003).

Slide 6

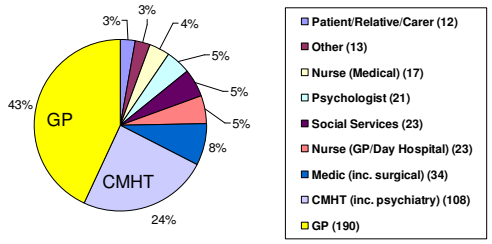
Aim 1: Describing referral characteristics

Age & Gender

	No. of referrals	As % of total referrals	Mean age (S.D)
FEMALE	304	68%	73 (7)
MALE	143	32%	74 (7.1)
TOTAL	447	100%	74 (7.1)

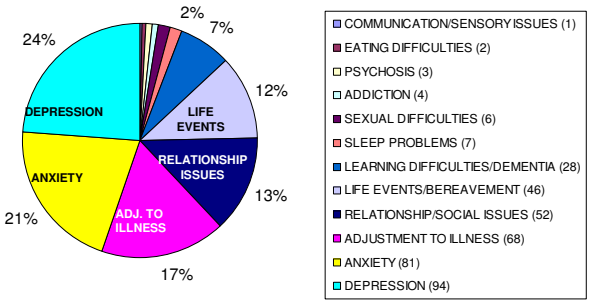
Slide 7

Sources of referrals (6 cases excluded)



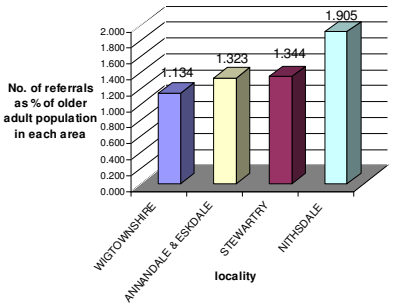
Slide 8

Diagnosis (60 cases excluded)



Slide 9

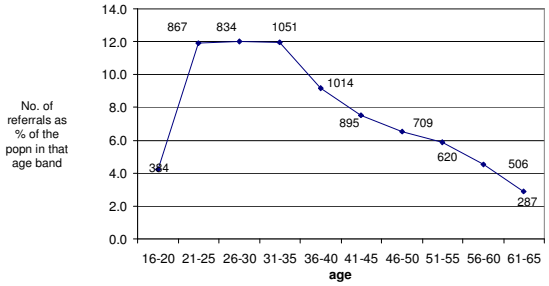
Referrals by locality



Area	Population over 65yrs	No. of referrals
Wigtownshire	6173	70
A & E	7861	104
Stewartry	5506	74
Nithsdale	10446	199

Slide 10

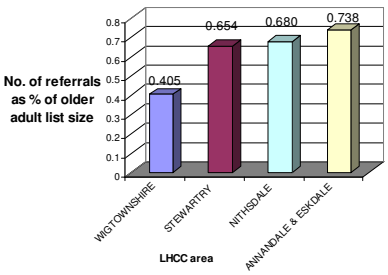
AMH referrals over a 4 year period by age band



Slide 11

Aim 2 – To examine patterns of GP referrals to the Older Adult service

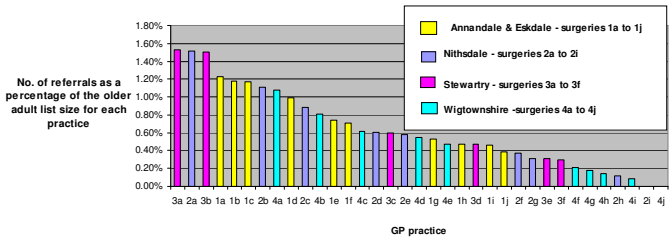
GP Referrals by locality



Area	Popn over 65 years	No. of referrals
Wigtownshire	6173	25
Stewartry	5506	36
Nithsdale	10446	71
A & E	7861	58

Slide 12

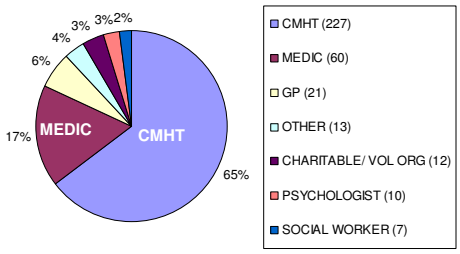
GP referrals by individual practice



Slide 13

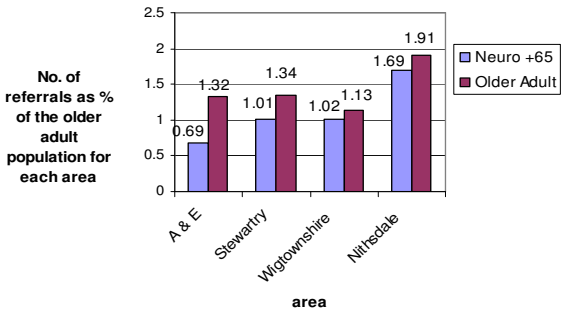
Aim 3: To examine referrals of those +65yrs to the Neuropsychology service over 4 years (n=350)

Referring agents



Slide 14

Referrals of those over 65yrs to the Neuropsychology service compared to the Older Adult service



Slide 15

Limitations & Recommendations

- Population data, though most recent available, are two years out of date.
- During the audit, there was a period where Clinical Psychologist was absent, and clinicians from AMH covered the older adult service.
- It was initially the intention to examine reasons for referral. However, the data was incomplete, and lacked utility as it is inputted by administrative staff without reference to diagnostic coding systems.
- As sixty cases lacked a diagnosis on the system, there are issues as to generalisability of the findings.
- Clinicians also enter up to five diagnoses on the discharge summary form, yet it seems that over the period audit, only one diagnosis was regularly inputted for each patient. This affects evidence of comorbidity.

Appendix 1.2

Table: Frequency of referrals by individual GP practice

Surgery	No. of referrals	Population over 65 years	Ref as % of population
3a	7	458	**1.53%**
2a	12	793	**1.51%**
3b	12	797	**1.51%**
1a	4	326	**1.23%**
1b	10	850	**1.18%**
1c	7	599	**1.17%**
2b	23	2079	**1.11%**
4a	9	838	**1.07%**
1d	11	1105	**1.00%**
2c	10	1131	**0.88%**
4b	4	497	**0.80%**
1e	4	540	**0.74%**
1f	3	426	**0.70%**
4c	2	327	**0.61%**
2d	12	1972	**0.61%**
3c	7	1171	**0.60%**
2e	5	866	**0.58%**
4d	1	182	**0.55%**
1g	5	941	**0.53%**
4e	5	1058	**0.47%**
1h	6	1272	**0.47%**
3d	2	428	**0.47%**
1i	6	1286	**0.47%**
1j	2	516	**0.39%**
2f	2	539	**0.37%**
2g	6	1914	**0.31%**
3e	4	1299	**0.31%**
3f	4	1353	**0.30%**
4f	1	478	**0.21%**
4g	1	571	**0.18%**
4h	1	706	**0.14%**
2h	1	876	**0.11%**
4i	1	1184	**0.08%**
2i	0	276	**0.00%**
4j	0	332	**0.00%**
TOTAL	**190**	**29986**	

Appendix 2.1

British Journal of Obstetrics & Gynaecology – Notes for contributors

Instructions to authors

We give priority to papers containing original data, systematic reviews and commentaries suggesting innovative approaches to women's health problems. If the editors think that it is necessary to view the raw data described in a paper, the authors will be expected to provide these data on request. The requirements for authorship and for preparation of manuscripts submitted to BJOG are in accordance with the Uniform Requirements for Manuscripts Submitted to Biomedical Journals (http://www.icmje.org). The standards for the editorial process are in accordance with the Committee on Publication Ethics guidelines (www.publicationethics.org.uk) in A Code of Conduct for Editors of Biomedical Journals.

A QUOROM statement checklist is required for systematic review meta-analyses: www.consort-statement.org/QUOROM.pdf. Systematic reviews are welcome. They should be critical assessments of current evidence covering a broad range of topics of concern to those working in the field of obstetrics and gynaecology. Systematic reviews should be 4000–5000words (abstracts to be structured as above).
NB For advice on writing systematic reviews consult: The Cochrane Reviewers' Handbook: http://www.cochrane.org/resources/handbook

Layout of manuscripts

All manuscripts should be double-spaced in an A4-sized document. The manuscript text must be arranged consecutively in the following sequence:
1. Title Page, 2. Abstract (if required) 3. Main Body of Text 4. Acknowledgements, 5. Disclosure of Interests, 6. Contribution to Authorship, 7. Details of ethics approval, 8. Funding, 9. Reference List, and 10. Table/Figure Caption List.

Manuscripts should be written in clear concise English. 'Fetus' and 'fetal' should be spelt without 'o', and 'ise' spellings are preferred to 'ize' spellings. Numbers one to ten should be spelled out; for more than ten people, objects, days, months, etc., use Arabic numerals. 'Women' is generally preferred to 'patients' when reporting on obstetrics. 'Termination of pregnancy' is preferred to 'therapeutic abortion' and 'miscarriage' is preferred to 'spontaneous abortion'.

1. Title page

The title page of the text should include the following information:
full title of the paper
names of all co-authors, with their addresses clearly identified
name and contact details (address, telephone number, and email address) of the corresponding author responsible for checking proofs and distributing offprints
shortened running title of no more than 60 characters for continuation pages

Please note that to qualify for authorship an individual should meet these criteria: (a) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; (b) drafting the article or revising it critically for important intellectual content; and (c) final approval of the version to be published. Authors should meet conditions (a), (b), and (c). Contributors who do not qualify for authorship should be included in the Acknowlegments section.

2. Abstracts

A full structured abstract of no more than 250 words is required for main research articles, subdivided into the following sequential sections: Objective; Design; Setting; Population or Sample; Methods; Main Outcome Measures; Results; Conclusions; and Keywords. For Systematic Reviews, the abstract should be subdivided into the following sequential sections: Background; Objectives; Search Strategy; Selection Criteria; Data Collection and Analysis; Main Results; Conclusions; and Keywords.
Short communications, non-systematic reviews and surgical techniques require a 100-word 'block' style, non-structured abstract.

3. Main body of text
The text of main articles and short communications should be subdivided under the headings: Introduction, Methods, Results, Discussion and Conclusion. Case Reports should be in sections under the headings: Case Report and Discussion. Commentaries and Reviews should have headings appropriate to the article. Any abbreviations or acronyms used should be defined at first use in the main body of the article. Authors should always use the generic names of drugs unless the proprietary name is directly relevant. Any specialised equipment, chemical or pharmaceutical product cited in the text must be accompanied by the name, city and country of its manufacturer.

4. Acknowledgements
Include, for example, funding for OnlineOpen publication, or funding for writing or editorial assistance also include contributors who do not qualify as authors, with their contribution described.

5. Disclosure of Interests
These include relevant financial (for example patent ownership, stock ownership, consultancies, speaker's fees), personal, political, intellectual or religious interests. Please note that a conflict of interest should not prevent someone from being listed as an author if they qualify for authorship.

6. Contribution to Authorship
A paragraph explaining each author's contribution.

7. Details of Ethics Approval
Any reports of studies or trials involving human or animal subjects, or medical records should contain a statement, in this Details of Ethics Approval section, that the procedures of the study received ethics approval from the relevant regional or institutional ethics committee responsible for human experimentation or complied with regulations governing experimentation using animals. The date of approval and reference number must be supplied. If no ethics approval was received please explain why, also including an explanation as to how the study adhered to the World Medical Association Declaration of Helsinki: http://www.wma.net/e/policy/b3.htm
Editors will use their own experience to judge whether a paper should be published, and if deemed necessary by the Editors, cases will be submitted to COPE (Committee on Publication Ethics).

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10. Table/Figure Caption List
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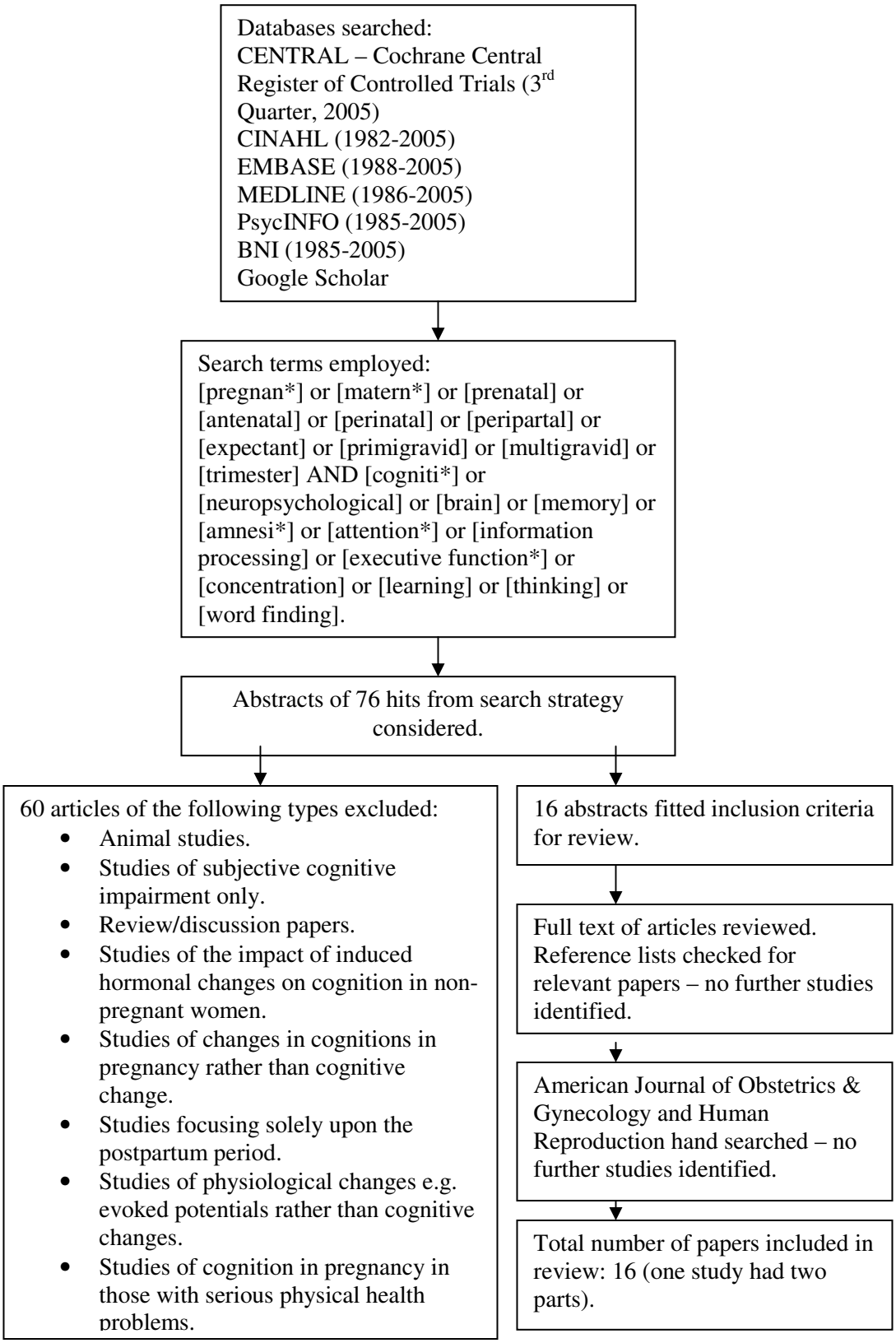
Study design and Statistics
The design of investigations, methods of analysis and the source of data should be described in sufficient detail to permit the study to be repeated by others, and must include specification of all statistical methods. Measurements should be expressed in SI units with the exception of haemoglobin (g/dL) and blood pressure (mmHg).

Appendix 2.2
Results of search strategy



Appendix 2.3

Studies included in review

Author	Year	Title
Brindle et al	1991	Objective and subjective memory impairment in pregnancy
Casey	2000	A longitudinal study of cognitive performance during pregnancy and new motherhood
Casey et al	1999	Memory in pregnancy II: Implicit, incidental, explicit, semantic, short-term, working and prospective memory in primigravid, multigravid and postpartum women
Christensen et al	1999	Pregnancy may confer a selective cognitive advantage
Condon et al	1991	Cognitive functioning during pregnancy: a controlled investigation using psychometric testing
Crawley et al	2003	Cognition in pregnancy and the first year post-partum
De Groot et al	2006	Differences in cognitive performance during pregnancy and early motherhood
De Groot et al	2003	Memory performance, but not information processing speed, may be reduced during early pregnancy
De Groot & Hornstra et al	2003	Selective attention deficits during human pregnancy
Harris et al	1996	Peripartal cognitive impairment : secondary to depression?
Janes et al	1999	Memory in pregnancy I: Subjective experiences and objective assessment of implicit, explicit and working memory in primigravid and primiparous women
Keenan et al	1998	Explicit memory in pregnant women
McDowall et al	2000a	Implicit and explicit memory in pregnant women: An analysis of data-driven and conceptually driven processes
McDowall et al	2000b	Implicit and explicit memory in pregnant women: An analysis of data-driven and conceptually driven processes
Schneider	1989	Cognitive performance in pregnancy
Silber et al	1990	Temporary peripartal impairment in memory and attention and its possible relation to oxytocin concentration
Vanston et al	2005	Selective and persistent effect of foetal sex on cognition in pregnant women

Appendix 2.4

Quality assessment using aspects of Cho & Bero (1994) and SIGN (2004)

Question	Aspect of Methodological Quality	Score
1	Study Design (Prospective longitudinal using those who do not fall pregnant as controls = 5 points, prospective longitudinal non-pregnant not examined = 4 points, crosssectional longitudinal with controls = 3 points, crosssectional longitudinal without controls = 2 points, crosssectional with controls = 1 point, crosssectional without controls = 0 points)	0,1,2,3,4,5
2	If longitudinal, were both groups tested on the same number of occasions?	0,1
3	Study Question	0,1,2
4	Q'n sufficiently described?	0,1,2
5	Design approp to answer q'n?	0,1,2
6	The inclusion criteria were specified (for both experimental group and controls where appropriate)	0,1,2
7	The exclusion criteria were specified (for both experimental group and controls where appropriate)	0,1,2
8	Were participants approp to study q'n?	0,1,2
9	Were controls appropriate? (N/A if none)	0,1,2
10	Were there more than 27 participants in each group?	0,1
11	If less than 27, was there a sample size justification before the study?	0,1,2
12	Were participants randomly selected from target popn?	0,1,2
13	If randomly, was the method of random selection well-described? (N/A if non-random)	0,1,2
14	If blinding of participants was possible, was it reported? (N/A if not possible)	0,1,2
15	Were attrition of participants and reasons for attrition reported?	0,1,2
16	Is evidence from other sources is used to demonstrate that the method of outcome assessment is valid and reliable?	0,1,2
17	If any outcome measures are adaptations of standardised assessments, are the adaptations are well described?	0,1,2
18	Were known confounding demographic factors accounted for by study design? (N/A if no known)	0,1,2
19	Were the groups comparable at baseline on demographic factors?	0,1,2
20	Were known confounding clinical/health factors accounted for by study design? (N/A if no known)	0,1,2
21	Were known confounding demographic factors accounted for by analyses? (N/A if no known)	0,1,2
22	Were known confounding clinical/health factors accounted for by analyses? (N/A if no known)	0,1,2
23	Were the statistical tests stated?	0,1,2
24	Were statistical analyses appropriate?	0,1,2
25	Were exact p values or confidence intervals reported for each test?	0,1,2
26	Were post-hoc calc or confidence intervals reported for n.s. results?	0,1,2
27	For those who completed the study, were the results completely recorded?	0,1,2
28	Do the findings support the conclusions?	0,1,2

APPENDIX 2.5 – SUMMARY OF METHODOLOGIES (SEE SEPARATE DOCUMENT)

APPENDIX 2.5 CONT'D

APPENDIX 2.6 – SUBJECTIVE COGNITIVE MEASURES (SEE SEPARATE DOCUMENT)

APPENDIX 2.6 CONT'D

APPENDIX 2.7 – RESULTS IN TERMS OF OBJECTIVES (SEE SEPARATE DOCUMENT)

APPENDIX 2.8 – QUALITY QUESTIONS & RESPONSES (SEE SEPARATE DOCUMENT)

Appendix 3.1

British Journal of Obstetrics & Gynaecology - Notes for submission for authors.

Instructions to authors: Original research may be reported as a main article or as a short communication. A main article of between 4000 and 5000 words may present the outcome of a large trial, case control, observational or retrospective study; these must have a full structured abstract.

Layout of manuscripts

All manuscripts should be double-spaced in an A4-sized document. The manuscript text must be arranged consecutively in the following sequence:
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1. Title page

The title page of the text should include the following information:
full title of the paper
names of all co-authors, with their addresses clearly identified
name and contact details (address, telephone number, and email address) of the corresponding author responsible for checking proofs and distributing offprints
a shortened running title of no more than 60 characters for continuation pages

Please note that to qualify for authorship an individual should meet these criteria: (a) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; (b) drafting the article or revising it critically for important intellectual content; and (c) final approval of the version to be published. Authors should meet conditions (a), (b), and (c). Contributors who do not qualify for authorship should be included in the Acknowledgments section.

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4. Acknowledgements

Include, for example, funding for OnlineOpen publication, or funding for writing or editorial assistance also include contributors who do not qualify as authors, with their contribution described.

5. Disclosure of Interests

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Editors will use their own experience to judge whether a paper should be published, and if deemed necessary by the Editors, cases will be submitted to COPE (Committee on Publication Ethics).

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10. Table/Figure Caption List
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Study design and statistics
The design of investigations, methods of analysis and the source of data should be described in sufficient detail to permit the study to be repeated by others, and must include specification of all statistical methods. Measurements should be expressed in SI units with the exception of haemoglobin (g/dL) and blood pressure (mmHg).

See, http://bjog.allentrack.net/cgi-bin/main.plex?form_type=display_auth_instructions&j_id=42 for details.

Appendix 3.2

Major Research Project Proposal – list of amendments

The following amendments to the proposal were made during the process of obtaining ethical approval;

Research Question & Design (p.8-9)

Section to be removed and replaced with;

Are women making 'informed choices' with regard to Combined Ultrasound & Biochemical (CUB) screening in the first trimester of pregnancy?
A high level of evidence-based information is routinely provided to women at the Queen Mother's Maternity, hence it is expected that they will be relatively well informed. As studies have found that offering screening at the first appointment promotes more informed choices, it is presumed that the current study will support this finding.

7. Women will be well-informed with regard to CUB screening, in that the majority will score above a cut-off on a measure of knowledge based on the RCOG guidelines. This is founded upon previous research suggesting that a providing high level of evidence-based information, as is the case at the Queen Mother's Maternity, promotes better knowledge of screening (Goel et al., 1996).

8. Demographic factors will have an impact upon knowledge in that younger (Marteau et al., 1988); primigravid (Marteau et al., 1988) women of lower educational levels (Santalahti et al., 1998) or from ethnic minorities (Dormandy et al., 2005) will be less well informed.

9. The women receiving a home visit by a Community Midwife prior to their appointment, will be better informed than others, having had an opportunity to discuss screening prior to completing the questionnaire.

10. Women's attitudes will be in line with their behavioural intention in that the majority of women with positive attitudes will intend to have screening, those with negative attitudes will intend not to have screening and those with neutral attitudes will be undecided (based upon the research of Berne-Fromell, 1984).

11. Women's attitudes will be the most important factor in determining behavioural intention in that for the majority of women, there will be a stronger relationship between attitude and behavioural intention than perceived behavioural control or subjective norm components of the TPB (based upon the research of Marteau et al., 1988).

12. Women will make 'informed choices', as determined by support for hypotheses 1 and 4 & 5 above.

This will be a prospective non-experimental study of women after they have been offered the screening test, but before the opportunity for testing.

Measures (p.10)

Paragraph 2: *"Hence it is the intention to give semi-structured pilot questionnaires to approximately 25 individuals to obtain indirect measures in the form of commonly held beliefs in relation to each TPB construct."* Replace '25 individuals' with '50 individuals'.

Recruitment & Procedure (p.11)

Paragraph2: *"It is intended that the pilot questionnaires will be sent to all women being offered screening appointments within a three-day period (or until 25 questionnaires are returned)."* Replace with; *"It is intended that the pilot questionnaires will be sent to 50 women being offered screening appointments within a three-day period."*

Paragraph 3: *"It is intended that women will have the opportunity to return the questionnaire in a provided sealed envelope when women attending their appointment. This will be anonymous as women will not be asked to provide any identifiers on the questionnaire. Posters/leaflets will also be placed in the reception areas and copies given to receptionists, should anyone wish to complete a questionnaire just before their scan."* replaced with *"It is intended that women will to return the questionnaire in the freepost envelope provided, prior to attending their appointment. This will be anonymous as women will not be asked to provide any identifiers on the questionnaire."*

Time Frame (p.12)

Paragraph 1: *"It is expected that the data will be collected over a period of 2 months."* Change 2 months to 1 month.

Power Calculations (p.12)

Add; *"Should sample size permit comparison between groups, Michie et al. (2004) found that women receiving screening as part of a routine visit were more likely to intend to accept (X = 8.2 SD 4.38) than those having to attend a separate appointment (X = 7.09 SD 4.18). To achieve a similar finding aiming for an R^2 of 0.8, a sample size of 19 per group would be required."*

Analyses (p.12-13)

Section to be removed and replaced with;

Hypothesis 1: Analysis will comprise of a simple calculation percentage of women scoring above a cut-off on the RCOG awareness elements of the questionnaire. Within this, percentage of correct responses for each question will be calculated to determine any particular areas of weakness across the sample.

Hypothesis 2: Demographic influences will be examined by performing correlations between each one and raw knowledge score.

Hypothesis 3: Whether women receiving home visits will be better informed than others will be examined by performing t-tests using visit/no visit as the independent variable and knowledge score as the dependent variable.

Hypothesis 4: Correlations will be performed between TPB components and intention, to determine whether a stronger relationship exists with attitude than other factors.

Hypothesis 5: Will be examined using multiple regression analyses, unless there is a significant skew in the data necessitating use of non-parametric measures. To control for/examine the effects of the demographic variables, a hierarchical regression analysis could be conducted using behavioural intention as the dependent variable and demographic factors as predictors at the first level, then the three other TPB components at the second.

Additional analyses: To determine validity of the indirect items, bivariate correlations between direct and indirect scores for each TPB component could be carried out.

Possible practical issues & costing (p.14)

Remove: "There is also a practical issue of ensuring that reception staff collect completed questionnaires."

Appendix 3.7 – Demographic aspects of questionnaire

Question 5: Remove "Do you have any other children?" *and replace with* "Have you ever been pregnant before?".

Question 6 & 7: Remove "Have you every suffered a miscarriage?" *and* "Have you ever had a termination?"

Add further question: "Which antenatal clinic will you be attending?"

Appendix 3.8 – RCOG aspects of questionnaire

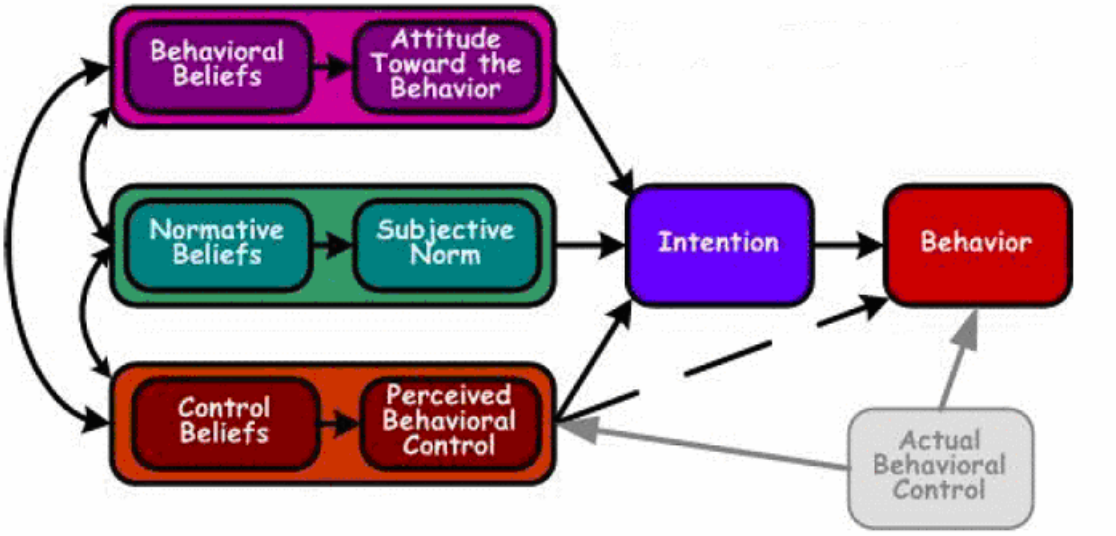
Remove: Questions 2, 6, 8 & 9.

Question 3: Replace 'positive' with 'high chance'.

Question 4: Replace 'negative' with 'low chance'.

Appendix 3.3

Theory of Planned Behaviour model



Ajzen (2002) Constructing a TPB Questionnaire

Appendix 3.4

RCOG areas of awareness

A report by the Royal College of Obstetricians & Gynaecologists (1993) outlined the following eight areas that women should be aware of when making screening choices;

1. The condition being screened for
2. The likelihood of detection
3. The method of testing
4. The meaning of a positive screening result
5. The meaning of a negative screening result
6. The options following a positive screening result e.g. diagnostic testing
7. Then options following a positive diagnostic test e.g. termination/continuation, counselling
8. How they can obtain further information at any stage

Appendix 3.5

Sample theory of planned behaviour questionnaire and demographic questions

The purpose of this questionnaire is to look at how much people know about Combined Ultrasound & Biochemical screening (CUB screening). This is the sort of screening that you will be offered between 10 and 14 weeks of pregnancy. It involves having an ultrasound scan followed by a blood test.

First, if you could answer some general questions about yourself.

Please state your age	…….. years

	Please tick one:	
What is your current relationship status?	single	
	in a relationship	
	married	

What ethnic group would you consider yourself as?	Asian	
	Black	
	Chinese	
	Mixed	
	White	

What level of eduction have you reached so far?	School	
	College	
	University	
	Postgraduate	

	Please circle your answer:	
Do you have any other children?	yes	no
If you answered yes, how many?.....		

Have you ever suffered a miscarriage?	yes	no
If you answered yes, how many times?.....		

Have you ever had a termination?	yes	no
If you answered yes, how many times?.....		

Are either you or your partner a car owner?	yes	no

Are you employed at present?	yes	no
If yes, please state your occupation……		

CONT'D

The following questions are all related to Combined Ultrasound & Biochemical screening. Please indicate your answers by circling the response which you think fits best, for example;

I expect to have CUB screening during this pregnancy	Strongly disagree	1	2	3	4	5	6	7	Strongly agree

Please answer as many questions as possible. Thank you.

I expect to have CUB screening during this pregnancy	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
I want to have CUB screening during this pregnancy	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
I intend to have CUB screening during this pregnancy	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Having CUB screening will be…..	Bad for me	1	2	3	4	5	6	7	Good for me
If I have CUB screening, it will allow my partner to feel more involved	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
If I have CUB screening, it may reassure me that the baby is healthy	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
If I have CUB screening, I will become more attached to my baby emotionally	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
If I have CUB screening, it will allow early detection of any problems with the baby	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
My partner feeling more involved with my pregnancy is…..	Extremely undesirable	-3	-2	-1	0	1	2	3	Extremely desirable
(If you are not in a relationship please go to next question)									
Being reassured that my baby is healthy is…..	Extremely undesirable	-3	-2	-1	0	1	2	3	Extremely desirable
Becoming more emotionally attached to my baby is…..	Extremely undesirable	-3	-2	-1	0	1	2	3	Extremely desirable
Detecting any problems with my baby early is…..	Extremely undesirable	-3	-2	-1	0	1	2	3	Extremely desirable

CONT'D

I feel under social pressure to have CUB screening	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Most people who are important to me think that I should have CUB screening	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
I feel that my partner thinks that I... have CUB screening	Should	-3	-2	-1	0	1	2	3	Should not
I feel that my midwife thinks that I… have CUB screening	Should	-3	-2	-1	0	1	2	3	Should not
I feel that my GP thinks that I… have CUB screening	Should	-3	-2	-1	0	1	2	3	Should not
Whether my partner thinks I should/shouldn't have CUB screening matters to me	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Whether my midwife thinks I should/shouldn't have CUB screening matters to me	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Whether my GP thinks I should/shouldn't have CUB screening matters to me	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
It will be difficult for me to have CUB screening	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
I am confident that I would be able to have CUB screening if I wanted to	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
It is my decision whether or not I have CUB screening	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Having to take time off work makes it more difficult for me to have CUB screening.	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
(If you are not employed please go to next question)									
Having information leaflets makes it easier for me to have CUB screening	Strongly disagree	1	2	3	4	5	6	7	Strongly agree
Having to take time off work makes it…..	Less likely	-3	-2	-1	0	1	2	3	More likely
…..that I will have CUB screening. (If you are not employed please go to next question)									
Having information leaflets makes it…..	Less likely	-3	-2	-1	0	1	2	3	More likely
…..that I will have CUB screening									

Appendix 3.6

RCOG aspects of questionnaire

1. Which of the following does CUB screening involve?
(please tick as many as you think are correct)
- ☐ Giving a sample of blood
- ☐ Having a surgical procedure or 'operation'
- ☐ Having an ultrasound scan
- ☐ Giving a sample of urine

2. Which of these conditions might CUB screening be able to indicate a greater risk of?
(please tick as many as you think are correct)
- ☐ Down's syndrome
- ☐ Autism
- ☐ Severe forms of spina bifida
- ☐ Cerebral palsy

3. If CUB screening led to a woman being given a 'positive' result for one of the conditions you chose above, would this mean that…..
(please tick ONE answer you think is correct)
- ☐ Their baby definitely does not have that condition
- ☐ Their baby definitely does have that condition
- ☐ Their baby has a lower chance of having that condition
- ☐ Their baby has a higher chance of having that condition

4. If CUB screening led to a woman being given a 'negative' result for one of the conditions you chose above, would this mean that….
(please tick ONE answer you think is correct)
- ☐ Their baby definitely does not have that condition
- ☐ Their baby definitely does have that condition
- ☐ Their baby has a lower chance of having that condition
- ☐ Their baby has a higher chance of having that condition

5. If a woman was told that CUB screening indicated her baby was at higher risk of having one of the conditions you chose above, what options would she have?
(please tick as many as you think are correct)
- ☐ To continue with the pregnancy as normal
- ☐ To have a termination straight away
- ☐ To have diagnostic tests e.g. amniocentesis or chorionic villus sampling (CVS)
- ☐ To have treatment for the condition during pregnancy

6. If a woman was told that CUB screening indicated her baby was at higher risk of having one of the conditions you chose above, what chance would her baby have of having that condition?
(please tick ONE answer you think is correct)
- ☐ The baby definitely has the condition
- ☐ The baby has at least a 1 in 1000 chance of having the condition
- ☐ The baby has at least a 1 in 250 chance of having the condition
- ☐ The baby definitely does not have the condition

7.

If a woman decided to have a test like amniocentesis or chorionic villus sampling (CVS) and was given a 'positive' result for a condition, what would this mean?
(please tick ONE answer you think is correct)

- ☐ Their baby definitely does not have that condition
- ☐ Their baby definitely does have that condition
- ☐ Their baby has a lower chance of having that condition
- ☐ Their baby has a higher chance of having that condition

8.

If a woman had a 'positive' result from amniocentesis or chorionic villus sampling (CVS) what options would she have?
(please tick as many as you think are correct)

- ☐ To continue with the pregnancy as normal
- ☐ To have a termination straight away
- ☐ To have further tests
- ☐ To have treatment for the condition during pregnancy

9.

What did the information provided to you by the hospital advise you to do, if you felt that you needed information about screening in pregnancy?
(please tick as many as you think are correct)

- ☐ Call your midwife
- ☐ Ask your friends
- ☐ Read the information booklets given
- ☐ Look on the internet

APPENDIX 4.1 – LETTER OF ETHICAL APPROVAL

APPENDIX 4.1 CONT'D

Headed paper

Appendix 4.2

Information Sheet

Thank you for taking the time to read this information sheet. I am a Psychologist at the University of Glasgow. I am doing a study looking at **women's knowledge and feelings towards Down's Syndrome screening in pregnancy**.

What are the purposes of the study?

The Queen Mother's Maternity Hospital and the Health Centres linked to it, use a type of Down's syndrome screening known as '*Combined Ultrasound & Biochemical Screening'* or '*CUBS'*. Very few studies have been carried out which look at women's views of screening.

It is hoped that the results of the study may help us to understand women's feelings toward screening better, to determine whether women need more/different information and to improve the care that pregnant women receive.

What am I being asked to consider?

You are being invited fill in a questionnaire, which is part of a research study. Before you decide whether to complete the questionnaire, it is important for you to understand why the research is being done and what it will involve.

Why have I been chosen?

All women being invited for antenatal booking appointments from the 14th February are being invited to take part in this study. This is to get as broad a picture of women's views as possible.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part, you should keep this information sheet and sign the consent form on the next sheet. If you decide you do not want to take part, you do not have to do anything else. A decision not to fill in the questionnaire will not affect the standard of antenatal care you receive.

What do I have to do?

If you decided to take part you would first sign the consent form, then fill in the questionnaire. The questionnaire looks at what you know about screening. It then asks you what you think about having screening during your pregnancy.

Once you had completed the questionnaire, you would then place this and the consent form in envelope they came in and post it **as soon as possible**. Postage is **free** and the envelope does not need a stamp.

Are all the questions about screening?

No, some of the first questions are more general – they ask for some information about you e.g. your age, whether you are in a relationship, your occupation. We ask these questions to find out whether people in different situations or from different backgrounds have the same views of screening.

What are the possible disadvantages of taking part?
Being asked to fill in a questionnaire like this might make some people feel that they do not know enough about screening. If you were to feel this way you could return to the information provided in the pack you received, or contact your midwife should you have further questions.

What are possible benefits of taking part?
The information that we get from this study may help us to improve the care that you or other women receive in future pregnancies.

Will my taking part in this study be kept confidential?
Your decision to take part or not to take part will remain entirely confidential. The questionnaires do not ask you to provide your name and are numbered only for the purposes of sorting. No one will be able to identify you from your questionnaire. All information collected will be kept in a locked filing cabinet.

What will happen to the results of the research study?
Results will be used as part of the Doctorate in Clinical Psychology training course and will be submitted for publication in a scientific journal. This can take around two to three years.

Who do I contact if I am unhappy about an aspect of this study?
If you had a more informal complaint, you could contact myself at the address provided in the next section. If you wished to make a formal complaint about this study, you could contact NHS Greater Glasgow & Clyde at;

Dalian House
350 St Vincent Street
GLASGOW
G3 8YZ
Tel: 0141 201 4444

Who can I contact if I want more information?

If you wish to discuss anything that has been mentioned in this information, or have any questions about the study, please do not hesitate to contact me at the following address;

Clare McGowan
Trainee Clinical Psychologist
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 0607
Email:

You can also contact **Dr Sarah Wilson** at the same address.

Thank you for taking the time to read this information

Headed paper

Appendix 4.3

CONSENT FORM

Title of project: A study of women's knowledge and feelings towards screening in pregnancy.

Name of researcher: Clare McGowan

Please write your initials in the boxes below

1. I confirm that I have read and understand the information sheet for the above study. ☐

2. I understand that my participation is voluntary and that I am free to choose not to participate, without giving a reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Then please complete the following;

Your name	Date	Your signature

Appendix 4.4
Semi-structured questionnaire

This questionnaire looks at how much women know about Down's Syndrome screening, which is offered between 11 and 14 weeks of pregnancy. This test is also known as Combined Ultrasound & Biochemical (CUB) screening.

First, if you could answer some general questions about yourself.

1. How old are you? …….. years

2. What is your current relationship status?
   - ☐ single
   - ☐ married
   - ☐ in a relationship

3. What ethnic group do you consider yourself to be?
   - ☐ White
   - ☐ Black Caribbean
   - ☐ Black African
   - ☐ Black Other
   - ☐ Indian
   - ☐ Pakistan
   - ☐ Bangladesh
   - ☐ Chinese
   - ☐ Other

4. What level of education have you reached so far?
   - ☐ School
   - ☐ College
   - ☐ University
   - ☐ Postgraduate

5. Do either you or your partner own a car?
   - ☐ yes
   - ☐ no

6. Do you work?
   - ☐ yes
   - ☐ no

   If yes, please state your occupation
   ……

7. Have you ever been pregnant before?
   - ☐ yes
   - ☐ no

8. Have you ever had Down's Syndrome screening before?
   - ☐ yes
   - ☐ no

Now if you could answer some questions about Down's Syndrome screening itself.

9. Have you read the information sent to you about Down's Syndrome screening?
   - ☐ yes
   - ☐ no

10. Did you understand the information sent about Down's Syndrome screening?
    - ☐ yes
    - ☐ no

11. What does Down's Syndrome screening involve?
    (please tick as many as you think are correct)
    - ☐ Giving a sample of blood
    - ☐ Having an 'operation'
    - ☐ Having an ultrasound scan
    - ☐ Giving a sample of urine
    - ☐ **None of the above**
    - ☐ **Don't know**

12. If a woman was given a 'high chance' result from Down's Syndrome screening, would this mean that…..
    (please tick ONE answer you think is correct)
    - ☐ The baby definitely does not have Down's Syndrome
    - ☐ The baby definitely does have Down's Syndrome
    - ☐ The baby has a lower chance of having Down's Syndrome
    - ☐ The baby has a higher chance of having Down's Syndrome
    - ☐ **Don't know**

13. If a woman was given a 'low chance' result from Down's Syndrome screening, would this mean that….
(please tick ONE answer you think is correct)

- ☐ The baby definitely does not have Down's Syndrome
- ☐ The baby definitely does have Down's Syndrome
- ☐ The baby has a lower chance of having Down's Syndrome
- ☐ The baby has a higher chance of having Down's Syndrome
- ☐ **Don't know**

14. If a woman was given a 'high chance' result from Down's Syndrome screening, what options would she have?
(please tick as many as you think are correct)

- ☐ To continue with her pregnancy as normal
- ☐ To have a termination ('abortion') within a few days
- ☐ To have diagnostic tests such as amniocentesis or chorionic villus sampling (CVS)
- ☐ To have treatment for the condition during pregnancy
- ☐ **Don't know**

15. Please consider the following situation: A woman is given a 'high chance' result from Down's Syndrome screening. She then decides to have amniocentesis. Which of the following might she be told after having amniocentesis?
(please tick as many as you think are correct)

- ☐ She may be told that her baby definitely does not have Down's Syndrome
- ☐ She may be told that her baby definitely does have Down's Syndrome
- ☐ She may be told that her baby has a lower chance of having Down's Syndrome
- ☐ She may be told that her baby has a higher chance of having Down's Syndrome
- ☐ **Don't know**

The last set of questions involve your own views towards having Down's Syndrome screening.
Some questions ask you to write in your answer and other questions ask you to circle a response, for example;

Strongly disagree ◯2 3 4 5 6 7 Strongly agree

16.	I expect to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
17.	I want to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
18.	I intend to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
19.	Having Down's Syndrome screening will be…..	Bad for me	1 2 3 4 5 6 7	Good for me

20. What do you think are the **benefits**, if any, of having Down's Syndrome screening? (Please write as many as you can).

21. What do you think are the **disadvantages**, if any, of having Down's Syndrome screening? (Please write as many as you can).

22.	I feel under pressure from others to have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
23.	Most people who are important to me think that I should have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

24. Who do you think would **encourage** you to have Down's Syndrome screening during pregnancy, if anyone? (Please list as many people as you wish.)

25. Who do you think would advise you **against** having Down's Syndrome screening during pregnancy, if anyone? (Please list as many people as you wish.)

26. Whose views about whether you should have Down's Syndrome screening would matter most to you, apart from your own? (Please list as many people as you wish.)

27.	It would be difficult for me to have Down's Syndrome screening if I wanted to	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
28.	I am confident that I would be able to have Down's Syndrome screening if I wanted to	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
29.	It is my decision whether or not I have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

30. What factors, if any, make you feel more confident that you would be able to have Down's Syndrome screening if you wanted to?

31. What factors, if any, might make it more difficult for you to have Down's Syndrome screening if you wanted to?

32. Did an interpreter help you to fill in this questionnaire? yes ☐ no ☐

Thank you for your time. Please put the consent form and questionnaire in the freepost envelope they came in, to send them back as soon as possible.

Appendix 4.5

Final questionnaire

This questionnaire looks at how much women know about Down's Syndrome screening, which is offered between 11 and 14 weeks of pregnancy. This test is also known as Combined Ultrasound & Biochemical (CUB) screening.

First, if you could answer some general questions about yourself.

1. How old are you? …… years

2. What is your current relationship status?
   - ☐ single
   - ☐ in a relationship
   - ☐ married

3. What ethnic group do you consider yourself to be?
   - ☐ White
   - ☐ Black Caribbean
   - ☐ Black African
   - ☐ Black Other
   - ☐ Indian
   - ☐ Pakistan
   - ☐ Bangladesh
   - ☐ Chinese
   - ☐ Other

4. What level of education have you reached so far?
   - ☐ School
   - ☐ College
   - ☐ University

5. Do either you or your partner own a car? yes ☐ no ☐

6. Do you work? yes ☐ no ☐
   If yes, please state your occupation……

7. Have you ever been pregnant before? yes ☐ no ☐

8. Have you ever had Down's Syndrome screening before? yes ☐ no ☐

9. Which antenatal clinic will you be attending?
   - ☐ Queen Mother's
   - ☐ Clydebank
   - ☐ Drumchapel
   - ☐ Maryhill
   - ☐ Woodside

10. Have you received a visit from a community midwife? yes ☐ no ☐
    (Please note: this is only offered in certain areas)

Now if you could answer some questions about Down's Syndrome screening itself.

11. Have you read the information sent to you about Down's Syndrome screening? yes ☐ no ☐

12. Did you understand the information sent about Down's Syndrome screening? yes ☐ no ☐

13. What does Down's Syndrome screening involve?
    (please tick as many as you think are correct)
    - ☐ Giving a sample of blood
    - ☐ Having an 'operation'
    - ☐ Having an ultrasound scan
    - ☐ Giving a sample of urine
    - ☐ **None of the above**
    - ☐ **Don't know**

14. If a woman was given a 'high chance' result from Down's Syndrome screening, would this mean that…..
    (please tick ONE answer you think is correct)
    - ☐ The baby definitely does <u>not</u> have Down's Syndrome
    - ☐ The baby definitely <u>does</u> have Down's Syndrome
    - ☐ The baby has a <u>lower</u> chance of having Down's Syndrome
    - ☐ The baby has a <u>higher</u> chance of having Down's Syndrome
    - ☐ **Don't know**

15. If a woman was given a 'low chance' result from Down's Syndrome screening, would this mean that….
(please tick ONE answer you think is correct)

- ☐ The baby definitely does not have Down's Syndrome
- ☐ The baby definitely does have Down's Syndrome
- ☐ The baby has a lower chance of having Down's Syndrome
- ☐ The baby has a higher chance of having Down's Syndrome
- ☐ **Don't know**

16. If a woman was given a 'high chance' result from Down's Syndrome screening, what options would she have?
(please tick as many as you think are correct)

- ☐ To continue with her pregnancy as normal
- ☐ To have a termination ('abortion') within a few days
- ☐ To have diagnostic tests such as amniocentesis or chorionic villus sampling (CVS)
- ☐ To have treatment for the condition during pregnancy
- ☐ **Don't know**

17. Please consider the following situation: A woman is given a 'high chance' result from Down's Syndrome screening. She then decides to have amniocentesis. Which of the following might she be told after having amniocentesis?
(please tick as many as you think are correct)

- ☐ She may be told that her baby almost certainly does not have Down's Syndrome
- ☐ She may be told that her baby almost certainly does have Down's Syndrome
- ☐ She may be told that her baby has a lower chance of having Down's Syndrome
- ☐ She may be told that her baby has a higher chance of having Down's Syndrome
- ☐ **Don't know**

This set of questions ask about your views towards having Down's Syndrome screening.
Please choose an answer for each by circling a resonse, for example;

Strongly disagree ◯2 3 4 5 6 7 Strongly agree

18.	I expect to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
19.	I want to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
20.	I intend to have Down's Syndrome screening during this pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
21.	Having Down's Syndrome screening will be…..	Bad for me	1 2 3 4 5 6 7	Good for me
22.	If I have Down's Syndrome screening, it will give me the information I need to make decisions during my pregnancy	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
23.	If I have Down's Syndrome screening, it may reduce my worry by reassuring me that the baby has a lower chance of having this condition	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

24.	If I have Down's Syndrome screening, it will give me more time to prepare for the possibility of having a baby with this condition	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
25.	If I have Down's Syndrome screening, I may be given a 'false negative' result. [For example being told that your baby has a lower chance of having Down's Syndrome, then giving birth to baby with this condition].	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
26.	If I have Down's Syndrome screening, I may be given a 'false positive' result. [For example being told that your baby has a higher chance of having Down's Syndrome, then giving birth to a healthy baby].	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
27.	If I have Down's Syndrome screening, the result I am given may lead me to decide to have diagnostic tests, which carry a risk of miscarriage	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
28.	Getting the information I need to make decisions involving my pregnancy is….	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable
29.	Reducing my worry that the baby may have Down's Syndrome is…..	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable
30.	Having more time to prepare for the possibility of having a child with Down's Syndrome is….	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable
31.	Getting a 'false negative' result is….	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable
32.	Getting a 'false positive' result is….	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable
33.	Being given a result which leads me to have diagnostic tests (which carry a risk of miscarriage) is….	Extremely undesirable	1 2 3 4 5 6 7	Extremely desirable

34.	I feel under pressure from others to have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
35.	Most people who are important to me think that I should have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
36.	I feel that my partner thinks that I should have Down's Syndrome screening (If you are currently single please go to the next question)	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
37.	I feel that my health professionals (doctors, midwives, obstetricians) think that I should have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
38.	I feel that my family think that I should have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

39.	I feel that my friends think that I should have Down's Syndrome screening.	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
40.	Whether my partner thinks I should/shouldn't have Down's Syndrome screening matters to me (If you are single please go to the next question)	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
41.	Whether my health professionals think I should/shouldn't have Down's Syndrome screening matters to me	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
42.	Whether my family think I should/shouldn't have Down's Syndrome screening matters to me	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
43.	Whether my friends think I should/shouldn't have Down's Syndrome screening matters to me	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

44.	It would be difficult for me to have Down's Syndrome screening if I wanted to	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
45.	I am confident that I would be able to have Down's Syndrome screening if I wanted to	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
46.	It is my decision whether or not I have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
47.	Having to take time off work makes it more difficult for me to have Down's Syndrome screening (if you are not employed please go to the next question)	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
48.	The distance that I live from the antenatal clinic makes it more difficult for me to have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
49.	Having information leaflets makes it easier for me to have Down's Syndrome screening	Strongly disagree	1 2 3 4 5 6 7	Strongly agree
50.	Knowing that Down's Syndrome screening is available to everyone, makes it easier for me to have it if I wanted to	Strongly disagree	1 2 3 4 5 6 7	Strongly agree

51.	Having to take time off work makes it….. …..that I will have Down's Syndrome screening. (If you are not employed please go to next question)	Less likely	1 2 3 4 5 6 7	More likely
52.	The distance I live from the clinic makes it….. …..that I will have Down's Syndrome screening	Less likely	1 2 3 4 5 6 7	More likely
53.	Having information leaflets makes it….. …..that I will have Down's Syndrome screening	Less likely	1 2 3 4 5 6 7	More likely
54.	Knowing that Down's Syndrome screening is available to everyone makes it…. …..that I will have Down's Syndrome screening	Less likely	1 2 3 4 5 6 7	More likely

Thank you for your time.
Please post the questionnaire and consent form free of charge using the envelope they came in.