Identifying barriers and facilitators to cancer screening uptake by people living with a diagnosis of mental illness: a qualitative investigation to inform policy and practice.

Final Report

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Contents

Executive Summary

Introduction: This document details the findings from a qualitative study designed to understand what helps and what hinders people living with a diagnosis of mental illness (PLWDMI) to take up the cancer screening tests for cervical, breast and bowel cancer currently offered by the NHS Cancer Screening Programmes in England.

Background: PLWDMI are three times more likely than the general population to die from cancer once diagnosed [1]. Mortality can be reduced through early detection via cancer screening. Cancer screening uptake is sometimes lower in PLWDMI than in the general public [2]. This study was conducted to identify the barriers to and facilitators of cancer screening in this population.

Methods: In depth, face to face or telephone interviews, informed by a topic guide, were conducted with PLWMDI eligible for the three national cancer screening programmes (breast, bowel, cervical) and with mental health and cancer screening professionals. Participants were recruited from inner city, suburban and rural locations (London and Dorset). Data collection and analysis were iterative. Framework analysis was used to identify themes relating to barriers and facilitators of cancer screening uptake.

Findings: Interviews were conducted with 45 PLWDMI (aged 26-73, 6 male, with a range of psychotic and non-psychotic diagnoses), 29 mental health professionals (18 from mental health nursing, 3 occupational therapists, 1 social worker, 1 psychiatrist, 4 support workers, and 2 inpatient staff) and 11 staff involved in screening delivery (5 breast screening unit staff, 2 practice nurses, 2 sexual health clinic nurses, 1 GP, 1 public health professional).Themes were identified for each group (PLWDMI, mental health professionals, screening professionals). Each theme is comprised of a set of barriers and facilitators.

People Living With a Diagnosis of Mental Illness:
Knowledge of screening. Barriers were: not knowing what to expect or what to do; feeling unsure of the need for screening; finding it difficult to process information due to mental health problems. Facilitators were: wanting to be informed; understanding the benefits of screening; encouragement and information from friends, family or health care professionals.

Motivation to attend**.** Barriers were: cancer screening perceived to be an additional burden; mental health symptoms reducing motivation for self care. Facilitators were: feeling ‘health conscious’; being anxious to avoid further problems; physical symptoms e.g. finding a lump.

Anticipation of positive or negative experience. Barriers were: past negative experience of screening; feelings of embarrassment around procedures; finding procedures traumatising; fear of bad news. A facilitator was having had a past positive experience.

Accommodation of mental health needs by physical health professionals. Barriers were: a lack of understanding of mental illness in screening professionals; staff being rushed; staff being rough; screening environments can aggravate mental health problems; mental health-related incidents leading to exclusion from a general practice. Facilitators were: staff being understanding; staff knowledge of mental illness.

Access to screening. Barriers were: difficulties booking appointments; transport difficulties (often exacerbated by mental or physical health problems); difficulty remembering appointments; difficulty leaving the house due to mental health problems; difficulty taking time off. Facilitators were: familiar location; receiving reminders, though some participants experienced paranoia around reminders or felt they were intrusive.

Relationships with health care staff. Barriers were: being made to feel like a burden on the health service; having a poor relationship with their GP; diagnostic overshadowing; stigma of mental illness.

Facilitators were having a good relationship with their GP; having a good relationship with practice nurses; continuity of care.

Screening professionals:
Approaches to meeting complex needs. Barriers were: lack of knowledge about mental illness; lack of time (to meet mental health needs). A facilitator was screening professionals being able to identify potential emotional and practical barriers to screening uptake for PLWDMI.

Attitude to PLWDMI. A barrier was that screening professionals sometimes find complex patients difficult. A facilitator was that staff members were motivated to encourage screening for all groups.

Communication skills. A barrier was that communication skills training was not available to all screening professionals. Facilitators were: the importance of good communication was recognised; confidence to screen anyone was associated with a professional feeling that they had good communication skills.

Integrated care. Barriers were: no way of knowing of patients' needs in advance (the onus is on the PLWDMI to call ahead, which can be difficult); computer systems are not linked across services, which makes information sharing difficult. Facilitators were: Practice Nurses are able to access patient records; reactive measures are in place in both primary care and breast screening services (e.g. longer appointments or additional support for staff) if notice is given.

Mental health professionals:
Knowledge/confidence to promote screening. Barriers were: lack of knowledge about screening programmes and procedures; promotion of cancer screening was not prioritised; no structured behaviour change approach is used routinely for health promotion. Facilitators were: health promotion was considered part of their role; an awareness that PLWDMI are at risk of cancer; recognising that diagnostic overshadowing is a problem.

Integrated care. Barriers were: lack of collaboration between different agencies involved in caring for PLWDMI (i.e. between primary and secondary care and between mental health and cancer screening services); lack of a clear process for promoting cancer screening uptake; mental health professionals sometimes lack physical health expertise; stigma of mental illness among non-mental health professionals. A facilitator was that mental health professionals understood the emotional and practical barriers to screening uptake for PLWDMI.

Health service delivery factors. Barriers were: not feeling responsible for cancer screening promotion in PLWDMI; lack of the resources; patient's mental state (some patients are too unwell for screening to be promoted and have more immediate needs). Facilitators were: a willingness to promote screening; cancer screening promotion could be included in routine health promotion.

Across the three participant groups, barriers to and facilitators of cancer screening uptake by PLWDMI can be summarised as relating to five overarching themes: knowledge of screening programmes and processes, knowledge of and attitudes regarding mental illness, health service delivery factors, PLWDMI's beliefs and concerns, practicalities for PLWDMI.

Discussion PLWDMI and NHS staff have identified service delivery related and personal factors which hinder and which help uptake of different types of cancer screening. Some of the identified factors, such as access difficulties and lack of knowledge or motivation, are relevant to other disadvantaged populations. Other factors such as failure by services to accommodate mental health needs, staff attitudes to PLWDMI, poorly integrated care and reports of poor relationships with health professionals appear specific, or especially important, to PLWDMI and need to be addressed. Barriers and facilitators to cancer screening uptake relate to different stages of the screening process; appropriate intervention is needed at each stage:

At the point of invitation to screening, or when sending out the FOBT for bowel cancer testing, PLWDMI will not receive post if they are admitted to hospital and will not be invited if they are not registered with a GP. Lack of integrated care means that mental health staff will not know if a PLWDMI is overdue for a test.

When attending for screening, the barriers and facilitators for individual PLWDMI will vary, so a personalised approach to addressing these is needed. This will be difficult if, as we have found, mental health professionals do not feel that this is part of their role or that they lack resources to do this. Tools to facilitate this, such as a shared decision aid which incorporates help to make an informed choice, are an evidence based method of facilitating behaviour change which could be used in a variety of settings. Staff and patient education and awareness raising is also needed and government could incentivise promotion of cancer screening through the QoF and CQUIN systems which are used to promote cardiovascular care in this population.

At the point of delivery of the screening test, individual needs will vary. Screening professionals are motivated to help, but often lack time or training to recognise and deal with mental health needs. Though reactive measures are available, this places the onus on the service user to make a request for help which may be difficult without reasonable adjustments in place. Staff training and specially targeted clinics may help.

Conclusions PLWDMI experience a range of barriers to receipt of cancer screening. These need to be addressed to ensure equality of care. Interventions are needed at the individual, policy and service delivery levels. GPs, cancer screening, mental health professionals and policy makers need to work together to develop an integrated approach to cancer screening in this population. This should be informed by evidence for other types of health promotion in disadvantaged populations such as tools to identify barriers and reasonable adjustments, shared decision aids, incentives or outreach services.

Principal Points

Barriers and facilitators

- There are multiple barriers and facilitators to uptake of cancer screening in PLWDMI
- Barriers and facilitators operate at service, practitioner and service user levels
- Different barriers and facilitators are identified by PLWDMI, screening professionals, and mental health professionals, although there are several areas of overlap
- Five overarching themes were identified: knowledge of screening programmes and processes, knowledge of and attitudes regarding mental illness, health service delivery factors, PLWDMI's beliefs and concerns, practicalities for PLWDMI.

Implications for policy and research

- Multiple approaches are needed to optimise cancer screening uptake in PLWDMI
- PLWMI are not a homogenous group in their needs and preferences regarding cancer screening.
- No one service location for any intervention that will meet the screening needs of all PLWDMI
- Interventions to increase uptake of cancer screening in the general population may not always be sufficient or effective for PLWDMI
- The identified barriers and facilitators to screening uptake are relevant at different stages of the screening process, namely recruitment to screening, attendance at screening, and performance of the screening test
- Potential interventions include: materials for meeting the learning needs of screening professionals, mental health professionals and PLWDMI; development of barriers identification and resolution tool for use with PLWDMI; provision of accommodations in screening practice to meet mental health-related needs; integrated care and support; and outreach-based approaches

Introduction

People with schizophrenia who develop cancer are three times more likely to die than those in the general population with cancer [1]. There is a range of explanations for this, but one reason may be low uptake of cancer screening tests [2]. Cancer screening is associated with reduced rates of morbidity and mortality [3-6]. It has been estimated that approximately one-third of cancer deaths could be prevented with early detection, of which screening is the most effective method [7].

The NHS Cancer Screening Programmes in England

The NHS Cancer Screening Programmes in England has three programmes: cervical, breast and bowel cancer screening. A key priority for the service is to ensure that all population groups enjoy fair access to its services.

Cervical screening

Cervical screening is offered to women aged 25 to 49 years every three years, and to women aged 50 to 64 years every five years. Women 65 years and over are only screened if they have not been screened since age 50 years or have had recent abnormal tests. Women who are registered with a GP will be invited to attend via a letter sent by the NHS Call and Recall system, which also keeps track of any follow up investigations.

The invitation letters explain how to book a test. Women may attend their GP, a well woman or sexual health clinic to obtain the test. During the test, a doctor or nurse inserts an instrument (a speculum) to open the woman's vagina and uses a small soft brush to sweep around the cervix (neck of the womb) to gather a sample of cells which are sent to a laboratory for analysis. Results are sent to women in writing. The aim of the test is to detect and treat early abnormalities which, if left untreated, could lead to cancer in a woman's cervix.

The percentage of women in the general population in the target age group (25 to 64 years) who were screened in the last five years was 78.6% in 2010/2011. If overall coverage of 80 per cent is achieved, it is suggested that a reduction in death rates from cervical cancer of around 95% is possible in the long term [8].

Breast screening

Women registered with a GP will be invited for screening within three years of their 50th birthday, with repeat invitations every three years until they are 70 years old. A randomised controlled trial of extending the age ranges for screening to women aged 47-49, and 70-73 started in 2010. Results of the trial will determine whether a roll out of age extension across the programme is warranted. Women receive an invitation letter, which usually specifies a pre-arranged appointment time at a mobile screening unit. Some screening is also undertaken in hospital-based clinics. An information leaflet about the risks and benefits of screening is included with the letter. Screening involves attending for x-rays (mammograms) of each breast which can detect small changes in breast tissue which may indicate cancer.

Research indicates that the NHS Breast Screening Programme lowered mortality rates from breast cancer in the 55-69 age group [9]. There has been widely reported controversy around breast cancer screening in terms of the potential for over-diagnosis (i.e. cancers detected and treated through screening which would not have been diagnosed in a woman's lifetime had screening not taken place). One study [10], conducted in 2010, suggests that the benefit of mammographic screening in terms of lives saved is greater than the harm in terms of over-diagnosis as between 2 and 2.5 lives are saved for every one over-diagnosed case.

Bowel cancer screening

Men and women aged 60 to 74 years and registered with a GP are offered bowel cancer screening every two years. People over 74 can request screening by telephoning a national helpline number. People will receive a letter explaining the programme and an information leaflet about the risks and benefits of screening. One week later a guaiac faecal occult blood test (FOBT kit is posted to them. People follow the written instructions (an animated video and British Sign language instructions can also be downloaded from the web, and an audio CD is available) to carry out the test at home. The test involves taking two small samples from three bowel motions, which are collected on a special card. The card is then sealed in a specially designed envelope, and posted to a laboratory for analysis.

The FOBT test detects tiny amounts of hidden (occult) blood which cannot normally be seen by the naked eye. Bowel cancer screening aims to detect bowel cancer at an early stage. It also detects polyps (small clumps of abnormal cells on the lining of the bowel) which are not cancers, but which may develop into cancers. Early detection of bowel cancer increases a person's chance of successful treatment and survival. Results of the FOBT test are posted to the person within two weeks. If occult blood is found, the person will be invited to attend for further investigation (a colonoscopy – examination of the inside of the large bowel).

Regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by 16% [11].

Cancer screening in people living with a diagnosis of mental illness

Like everyone in the general population, PLWDMI will receive invitations from the NHS to attend cervical, breast and bowel cancer screening. The mental health status of screening attendees is not recorded by the NHS Cancer Screening Programmes however, so rates of uptake in this population are unknown on a national basis.

In a review conducted by one of the current authors (EB) and others [2], evidence (n=12 studies: 8 in USA, 1 each in Iceland, Canada, Australia and the UK) was identified which suggests that adults with severe mental illness (bipolar disorder, schizophrenia, other psychoses, major depression and severe anxiety disorders) are less likely than other groups to receive screening for a range of cancers (cervical, breast, colorectal, and prostate cancer). A subsequent review [12] of breast and cervical cancer screening uptake in this population, but which also included studies in people with depression and anxiety disorders found 19 studies (15 conducted in the US, 2 in Canada 1 in Australia, 1 in the UK), and reported similar findings. However, a recent study [13], conducted in Maryland, USA, found higher cervical cancer screening rates in women living with a diagnosis of mental illness compared with controls without a diagnosis of mental illness.

Reasons for non-uptake of cancer screening by PLWDMI

Systematic reviews on cancer screening in PLWDMI report many barriers that are also experienced by the general population and by other disadvantaged groups. The few studies which have examined non-uptake of cancer screening by PLWDMI [14-17] have tended to focus on breast and cervical cancer screening. They have identified similar reasons for non-uptake for individuals with and without a diagnosis of mental illness including: low income, lack of transport, embarrassment, fear of pain and of receiving a cancer diagnosis, adverse prior experiences of screening, having experienced sexual violence, lack of reminders and lack of familiar care providers. However it is possible that these issues are more common in or more problematic for, PLWDMI than for other groups.

A further study [18]conducted in the USA suggests that poor communication between primary care and psychiatric services may contribute to reduced breast and cervical cancer screening uptake.

Service delivery factors are likely therefore to be especially important for this population. The authors of the study in Maryland, USA [13] conclude that their finding of higher screening uptake by women living with a diagnosis of mental illness may be explained by the study participants' participation in Maryland's Medicaid programme, which is situated in a wealthy state that has achieved relatively high grades for its public mental health system. Public health systems in the USA and the UK are very different. It is not known which service delivery factors are important for cancer screening uptake by PLWDMI in England.

The only study that we could identify which considered bowel cancer screening (as well as other types of cancer screening) in PLWDMI, was a scoping study of access by people from London's African Caribbean communities [19]. This study was commissioned by the NHS Cancer Screening Programme; telephone surveys about cancer screening delivery were conducted with staff from eight out of nine mental health providers running units caring for inpatient and detained patients in London (which have an over-representation of people from African Caribbean communities) and staff from five out of seven breast screening units and from all six bowel cancer screening centres in London. Key findings included that there exists no strategies to ensure that PLWDMI are included in cancer screening programmes, involvement in cancer screening by this population is not recorded, ethnicity of screening attenders is not recorded, the needs of inpatient groups are not considered, mental health and cancer screening service providers do not collaborate and people not registered with a GP are often effectively 'excluded' from cancer screening.

Interventions to improve access to cancer screening

It is well documented that PLWDMI experience more barriers when accessing physical healthcare than the general population [20]. To address this in the UK, incentive schemes such as the Quality and Outcomes Framework (QOF) [21] and the Commissioning for Quality and Innovation scheme [22] have been utilised. For instance, under QOF, GPs have been offered incentives to offer regular annual physical health reviews to people with diagnoses of schizophrenia or bipolar disorder, including, since 2006 [23], the offer of age and gender appropriate cancer screening. In secondary care mental health services, a clinical resource - the 'Lester tool' [24] - is in widespread use to support the implementation of the physical health CQUIN targets. These targets aim, through remuneration, to improve collaborative and effective physical health monitoring and management of common physical health conditions and risk factors in people with psychotic illnesses (e.g. smoking, lifestyle, obesity, hypertension, diabetes and hyperlipidaemia, though not specifically cancer screening). It is not known if these measures have an effect on cancer screening uptake by PLWDMI, but a recent report [20] that in some areas only 30% of PLWDMI had received their physical health review suggests that it is unlikely to have been effective so far.

Systematic reviews [25-27] have demonstrated the effectiveness of a range of interventions to increase cancer screening uptake in other populations. However, a Cochrane review[28], conducted by two of the current authors (EB, PW), found no trials of interventions to increase cancer screening uptake in PLWDMI. Identification of client-related and service-related barriers and facilitators to uptake of cancer screening specific to PLWDMI is an essential first step in informing which interventions are likely to be effective. This study set out to identify these barriers and facilitators.

Aims of the project

To understand the facilitators and barriers to cancer (cervical, breast, bowel) screening uptake as experienced by the person living with a diagnosis of mental illness. Findings will inform a special enquiry into cancer screening uptake in people living with a diagnosis of mental illness conducted by the NHS National Cancer Screening Service and future changes to services.

Research Methods

Design

Qualitative interview study with people living with a diagnosis of mental illness eligible for cancer screening, mental health professionals and professionals involved in the screening process.

Patient and Public Involvement

One of the study co-applicants is a mental health service user (as well as being a research academic). A further mental health service user was recruited to our project review group. Both have advised on rationale, methods, materials, data analysis, dissemination of findings and the project review group member has helped identify participants.

Sampling strategy

People living with a diagnosis of mental illness

The sampling frame was people living with a diagnosis of mental illness (bipolar disorder, schizophrenia, other psychoses, borderline personality disorder, major depression and severe anxiety disorders) who are eligible for cancer screening via the three national cancer screening programmes (breast, cervical and bowel).

They were recruited from the following sources:

1. Those managed within community mental health teams (CMHTs) and inpatient wards of South London and the Maudsley NHS Foundation Trust (SLAM). SLAM is part of King's Health Partners (KHP – a collaboration between Guys' and St Thomas', South London and the Maudsley and King's College Hospital NHS Trusts and King's College London). Recruitment was via the KHP mental health clinical academic groups (CAGS – operational groups of clinicians and academics designed to facilitate research across KHP).
2. Previous KHP research participants who had taken part in the MIRIAD study [29] and who have given consent to be contacted for future research.
3. Those managed within inpatient wards or CMHTs within Dorset Healthcare University NHS Foundation Trust.
4. Eligible contacts of enrolled participants or research team members (snowball sample sample).

Sources 1 and 2 were chosen to ensure access to people with a wide range of cultures, ethnicities and socio-economic positions, source 3 allowed us to gain insight from those living in rural communities more physically remote from screening services than those living in London, source 4 allowed recruitment of people in inpatient wards in South London who were well enough to be interviewed (the inpatient population in South London tends to be more severely ill than in Dorset, so we did not seek to recruit systematically from SLAM inpatient wards) and people currently managed solely in primary care. Recruitment of PLWDMI directly from primary care is problematic due to the small number of PLWDMI registered with each general practitioner (i.e. approximately 5 per GP).

We aimed to recruit a purposive sample of participants which varied according to mental health diagnosis, age, gender, screening service use / non-use and location in order to obtain the widest possible range of views. Study posters and flyers were left in clinical areas so that interested people could opt in to the study; people who had previously given consent to be contacted were contacted directly via post; snowballed participants were contacted via the means they specified to their study contact (e.g. telephone, post).

Professionals

Our sampling frame was professionals of any discipline working in any KHP or Dorset NHS trust who are involved in undertaking, promoting, or potentially promoting cancer screening. This included two groups:

1. Screening professionals: e.g. GPs, practice nurses, sexual health nurses (who currently deliver cervical screening and promote all types of screening) and breast screening unit staff.
2. Mental health (non-screening) professionals: e.g. mental health nurses, psychiatrists, occupational therapists and social workers, based in CMHTs or inpatient units who may be involved in promoting physical health reviews.

Recruitment was via study posters and flyers left in clinical areas and via snowballing.

All PLWDMI and professional participants were reimbursed for their travel expenses and for their time with a £20 *Love to Shop* Voucher.

Data collection

Data collection and analysis were iterative; interviews were conducted until the team agreed that theoretical saturation (i.e. no new ideas emerging from the data) had been reached. Participants were interviewed one to one either face to face (in NHS buildings or in a public space of the participant's choosing such as a café or park) or over the telephone according to the participant's preference. The option of choosing to be interviewed by email was also specified in the study information sheet. Interviews were semi-structured, informed by a topic guide, were audio recorded with consent and transcribed verbatim. Field notes were kept to inform analysis. Three staff members conducted interviews, all three were female, and although participants were offered the option of a male interviewer no participants requested this. Interviewers were aged 25, 50 and 53. Interviewer age and gender has the potential to have influenced interviewee data, for example, whether interviewers themselves are the ages to have been invited to screening. All were White British. Interviewers were all trained to deliver the interview questions in the same way, however different interviewers likely had a different style and this could have influenced data received. The main interviewer was a research assistant (AC) who conducted interviews in London and some in Dorset. The remainder of the Dorset interviews were conducted by a research assistant and a research nurse, both of whom received training from AC and EB. Participant identification numbers were allocated to each interviewer to avoid duplication e.g. 1-100, 100-200, 300-400.

Interview Schedule

The Theoretical Domains Framework (TDF) [30] informed the development of an interview schedule to identify the barriers and facilitators of attendance for cancer screening. The TDF is a theoretical framework for implementation research drawn from models to explain behaviour change [30]. The framework covers a set of domains comprising the main evidence-based factors influencing behaviour change, such as knowledge, beliefs about the consequences of the target behaviour, social influences such as the attitudes of close others, and the environmental context. Interview schedules appropriate for each sample (PLWDMI, mental health professionals, screening professionals) were developed (Appendices 1a, b, c).

Data analysis

The Framework Method of qualitative analysis was used to manage and classify the data [31]. The five key steps in the Framework approach include familiarisation, developing a thematic framework, indexing, charting, and interpretation. After familiarisation with the interview data, an analytic framework, based on a set of codes developed by the research team, was used to organise the data according to key categories. Indexing refers to the systematic application of codes from this framework to the dataset. The data were then summarised into a "case by category" matrix on a spreadsheet for interpretation and the development of explanatory themes or concepts. Displaying data in this way facilitates between and within case comparison.

The analytic framework for this study was broadly based on the domains that generated the interview schedule and all transcripts were coded according to this framework. Each transcript was coded according to these categories by one researcher and a sample of 30% of transcripts was independently assessed by another researcher to ensure agreement about the categories and whether selected data were representative of these. Following the data management process, over-arching themes were identified from reading the summaries in the charts and discussion with the research team. Relevant participant quotes to illustrate these themes were identified and agreed by the research team.

Initially data from each sample (PLWDMI, mental health professionals, screening professionals) were analysed separately, and themes for each group were identified. We sought evidence of disconfirming data. We then used a triangulation approach combining themes from patient and professional interviews. This involved producing a 'convergence coding matrix' to display barrier and facilitator findings from the different samples (patients and professionals) together. Next we considered where there was agreement, partial agreement, silence (a finding in one sample only) or dissonance between findings.

Findings

In total, 85 people were interviewed for this study between 1st of October 2014 and the 14th of April 2015. Participants (person living with a diagnosis of mental illness (PLWDMI), screening professionals, mental health professionals) and their location are described in Table 1.

Table 1. Category and location of participants

	Dorset	**London**	**Overall**
PLWDMI[a]	16	29	45
Screening professionals	0	8	11 [b]
Mental health professionals	10	19	29
Total	**26**	**56**	**85**

a People living with a diagnosis of mental illness; b Includes 3 participants recruited via snowballing who are based outside London (2 participants from Kent, 1 from Oxfordshire)

Interviews were conducted face to face (30 PLWDMI, 10 screening professionals, 20 mental health professionals) or over the telephone (15 PLWDMI, 1 screening professional, 9 mental health professionals). Two mental health professional interviews were terminated early at the request of the interviewee due to time pressure; follow up questions were answered by email.

Participant Characteristics

The characteristics of the three groups of participants (PLWDMI, screening professionals, mental health professionals) are shown, by location and overall, in Tables 2 – 4.

Table 2. Characteristics of people living with a diagnosis of mental illness

	London (n = 29) n / range (mean)	**Dorset (n 16) n/ range(mean)**	**Overall (n = 45) n (%)/ range(mean)**
Gender			
Female	26	13	39 (87%)
Male	3	3	6 (13%)
Age	33-70 (51)	26-73 (46)	26-73 (49)
Ethnicity[a]			

White British	15	16	31 (69%)
Black or Black British – African	3	0	3 (7%)
Black or Black British – Caribbean	5	0	5 (11%)
Mixed - White and Black African	2	0	2 (4%)
Mixed - White and Black Caribbean	2	0	2 (4%)
Other[b]	2	0	2 (4%)
Diagnosis[c]			
Schizophrenia	2	1	3 (7%)
Schizoaffective disorder	4	1	5 (11%)
Bipolar disorder[d]	12	3	15 (33%)
Other psychosis	1	1	2 (4%)
Depression[e]	4	3	7 (16%)
Depression & anxiety	3	2	5 (11%)
Anxiety disorder	1	1	2 (4%)
Personality disorder[d]	2	1	3 (7%)
Personality disorder & depression[e]	0	3	3 (7%)
Duration of diagnosis (years)	1-50 (20)	6-44 (15)	1-50 (19)
Current mental healthcare			
Inpatient	4	10	14 (31%)
Community Mental Health Team	10	6	16 (36%)
Primary care[f]	15	0	15 (33%)
Type(s) of screening discussed			
Cervical only	16	9	25 (56%)
Breast only	3	0	3 (7%)
Bowel only	3	3	6 (13%)
Cervical and breast	7	3	10 (22%)
Cervical, breast and bowel	0	1	1 (2%)

a Self-reported; b Arab (n = 1), Asian or black British – Indian (n = 1); c Self-reported, apart from in one case where participant did not know and information was obtained from clinical staff with participant consent; d Including 1 with co-morbid ADHD; e Including 1 with co-morbid anorexia; f The majority (12/15) of patients currently receiving primary care mentioned that they had received secondary mental health care in the past or were currently also using day centres indicating a high level of mental health problems

One participant (living in London) was not registered with a GP. Twelve of the 45 participants reported a family history of cancer. Our sample include PLWDMI who had missed, declined, ignored, or delayed cancer screening as well as those who had received screening on time.

Index of multiple deprivation scores indicated that on average the London sample was more deprived (IMD score of 27.82) than the Dorset sample (IMD score of 23.57).

Table 3. Characteristics of screening professionals in study sample

	N / range (mean)
Age	31-67 (48)
Gender	
Female	10
Male	1
Location	
London	8

Kent	2
Oxfordshire	1
Job roles	
General practitioner	1
Practice nurse	2
Sexual health clinic nurses	2
Breast screening radiographers	3
Breast screening service managers	2
Senior public health employee with screening remit	
Experience duration (years)	10 – 30 (19)

Table 4 Characteristics of mental health professionals in study sample

	London (n = 19) n / range (mean)	**Dorset (n = 10) n / range (mean)**	**Overall (n = 29) n / range (mean)**
Age	26-56 (42)	30-54 (41)	26-56 (42)
Job roles			
Mental health nurse	6	3	9
Mental health nurse practitioner	1	1	2
Social worker	1	0	1
Occupational therapist	2	1	3
Psychiatrist[a]	1	0	1
Support worker	1	3	4
Nursing assistant	0	2	2
Inpatient unit staff	2	0	2
Mental health academics[b]	3	0	3
Student mental health nurses	2	0	2
Duration of experience (years)	2-30 (10)	0.5-18 (13)	0.5-30 (11)

a Specialist registrar; b Two lecturers in mental health nursing and one research fellow and honorary consultant mental health nurse

Themes

Themes identified from the interview data are reported for each participant group. Barriers and facilitators to cancer screening uptake were identified for each theme. Similar barriers and facilitators arose from the data gathered from participants in Dorset and London; where differences were identified these are reported. In general, findings appeared consistent within groups, but where disconfirming evidence was identified descriptive quotes are provided. The main area of disconfirmation was regarding reminder letters which were regarded as helpful by some, but unhelpful and distressing by others. Quotes are identified by participant number, age, gender, role (PLWDMI or profession) and location (London or Dorset), and where the participant referred to only one type of screening this is indicated also. Themes commonly related to more than one type of cancer screening; the barriers and facilitators relevant to each type of screening are shown in Tables 5 to 7, which also relates each theme to domains from the Theoretical Domains Framework.

Table 5. Themes, barriers and facilitators identified in the sample of people living with a diagnosis of mental illness

Theme *(Theoretical Domain)*	**Barrier to uptake**	**Cervical**	**Breast**	**Bowel**	**Facilitator to uptake**	**Cervical**	**Breast**	**Bowel**
Knowledge and of screening *(Knowledge; skills; social influences; memory, attention & decision processes, beliefs about consequences)*	Not knowing what to expect or what to do	✓	✓	✓	Wanting to be informed	✓	✓	✓
	Unsure of need for screening	✓	✓	✓	Understanding of benefits of screening	✓	✓	✓
	Difficult to process information	✓	✓	✓	Encouragement	✓	✓	✓
Motivation to attend *(Motivation)*	Additional burden	✓	✓	✓	Feeling 'health conscious'	✓	✓	✓
	Mental health symptoms reduce motivation for self care	✓	✓	✓	Being anxious to avoid further health problems	✓	✓	✓
					Physical symptoms (e.g. finding a lump)	✓	✓	✓
Anticipation of negative or positive experience *(Emotion)*	Past negative experience	✓	✓	✓	Past positive experience	✓	✓	✓
	Embarrassment	✓	✓	✓				
	Traumatising	✓	✓	✓				
	Fear of bad news	✓	✓	✓				
Accommodation of mental health needs by NHS staff and services *(Behavioural regulation)*	Lack of understanding of mental illness in screening professionals	✓	✓	X	Staff being understanding	✓	✓	X
	Screening environment aggravates mental health symptoms	✓	✓	X	Staff knowledge of mental illness	✓	✓	X
	Staff can be rushed	✓	✓	X				
	Staff can be rough	✓	✓	X				
	Exclusion from GP registers	✓	✓	✓				
Access to screening	Appointment booking	✓	X	X	Familiar location	✓	✓	✓

(Environmental context & resources)	Transport difficulties	✓	✓	X	Reminders	✓	✓	✓
	Difficulty remembering appointments	✓	✓	✓				
	Difficulty leaving the house due to mental health problems	✓	✓	X				
	Taking time off	✓	✓	X				
Relationships with health care staff in general *(Emotion)*	Made to feel like a burden on health service	✓	✓	✓	Good relationship with GP	✓	✓	✓
	Poor relationship with GP	✓	✓	✓	Good relationship with Practice Nurse	✓	✓	✓
	Diagnostic overshadowing	✓	✓	✓	Continuity of care	✓	✓	✓
	Stigma of mental illness	✓	✓	✓				

Table 6. Themes, barriers and facilitators identified in the screening professional sample

Theme *(Theoretical Domain)*	**Barrier to uptake/delivery**	**Cervical**	**Breast**	**Bowel**	**Facilitator to uptake/delivery**	**Cervical**	**Breast**	**Bowel**
Approaches to meeting complex needs *(Knowledge; skills, environmental context & resources)*	Lack of knowledge of severe mental illness	✓	✓	X	Understanding of emotional and practical barriers to screening uptake for PLWDMI	✓	✓	✓
	Lack of time	✓	✓	X				
Attitude to PLWDMI *(Emotion; professional role & identity)*	Find complex patients difficult	✓	✓	X	Staff motivated to encourage screening for all groups	✓	X	X
Communication skills *(Skills)*	Communication skills training not available to all	X	✓	X	Importance of good communication skills recognised	✓	✓	X
					Confidence to screen anyone associated with good	✓	✓	X

					communication skills			
Integrated care *(Environmental context & resources; behavioural regulation)*	No means of knowing patient needs in advance	✓	✓	✓	Practice nurses can access patient record	✓	✓	✓
	Computer systems not linked	✓	✓	✓	Reactive measures in place if notice given	✓	✓	X

Table 7. Themes, barriers and facilitators identified in the mental health professional sample

Theme *(Theoretical Domain)*	**Barrier to uptake/promotion**	**Cervical**	**Breast**	**Bowel**	**Facilitator to uptake/promotion**	**Cervical**	**Breast**	**Bowel**
Knowledge and confidence to promote screening *(Knowledge; skills; social influences)*	Lack of knowledge of programme and /or procedures	✓	✓	✓	Health promotion seen as their role	✓	✓	✓
	Promotion of screening not prioritised	✓	✓	✓	Aware that PLWDMI are at risk of cancer	✓	✓	
	Lack of a structured behaviour change approach	✓	✓	✓	Diagnostic overshadowing known to be a problem	✓	✓	✓
Integrated care *(Skills; Environmental context & resources; behavioural regulation; emotion)*	Lack of collaboration between healthcare services	✓	✓	✓	Understanding emotional and practical barriers to screening uptake for PLWDMI	✓	✓	✓
	Lack of physical health expertise	✓	✓	✓				
	Stigma of mental illness	✓	✓	✓				

Health service delivery factors *(Environmental context & resources; behavioural regulation; professional role & identity)*	Cancer screening promotion not their responsibility	✓	✓	✓	Willingness to promote screening	✓	✓	✓
	Patient’s mental state	✓	✓	✓	Cancer screening promotion included in routine health promotion	✓	✓	✓
	Lack of resources	✓	✓	✓				

People living with a diagnosis of mental illness

Six themes were identified: Knowledge of screening; Motivation to attend; Anticipation of negative or positive experience; Accommodation of mental health needs by NHS staff and services; Access to screening; and Relationships with health care staff in general. These themes, the barriers and facilitators relating to the themes, and whether there was support for the barriers and facilitators across the different types of screening is shown in table 5.

Theme: Knowledge of screening

Barriers to screening uptake associated with this theme were: Not knowing what to expect or what to do; Unsure of need for screening; and Difficult to process information. Facilitators were: Wanting to be informed; Understanding benefits of screening; and Encouragement.

Barrier: Not knowing what to expect or what to do

Some Participants indicated that they were unsure of what to expect from screening prior to attending or taking part:

> *"I didn't know what to expect...I thought that was what they were going to do put me through a tunnel" (Participant 004, PLWDMI, female age 51, London, mammogram)*
>
> *"For about the last couple years I've been getting letters from them saying about cancer screening and they send a kit, but I don't know if I really understand a hundred percent how to work this kit" (Participant 047, PLWDMI male age 64, London, bowel)*

Barrier: Unsure of need for screening

Some participants seemed unconvinced that screening was necessary.

> *"As in like OK let's talk about why you need it and making me feel that I need to have it rather than feeling like well if they are only bothered to send a letter and nobody wants to talk about it then it makes you feel that well obviously I don't really need it." (Participant 110, PLWDMI, female age 32, Dorset)*

Others seemed unclear of the purpose of screening and thought that cancer screening was only used when a symptom was identified:

> *"There isn't anything unless you've got severe, unless you find symptoms yourself like breast screening or other cancers or cancer of the bowel you don't automatically get screened for them" (Participant 007, PLWDMI, female age 46, London)*
>
> *"Well that's the reason because I don't feeling anything at the moment so I thought if I need to do it then I will." (Participant 061, PLWDMI, male age 65, London)*

Barrier: Difficult to process information

Accessing and understanding information about screening was difficult for some participants due to poor concentration:

> *"I've just come out of a depression type of thing; I'm not really out of it properly, so at those sort of times I lose my confidence. I can't do anything; little things can become very, very big. The fact that I am feeling a little better in myself I think maybe I might be able to read and follow the instructions" (Participant 047, PLWDMI male age 64, London)*
>
> "I've got to read a lot of things. I find it hard to concentrate" *(Participant 022 PLWDMI female age 44, London)*

Facilitator: Wanting to be informed
Some participants felt that having more information about screening processes would help:

> *"Give them more information about it, leaflets, booklets for them to read up on it, send them to social people who have done it, network." (Participant 004 PLWDMI female age 51)*

> *"If they had a Facebook page telling you information about what cervical screening is, what it involves, is it painful, is it not painful because a lot of people my age don't even know what it is" (Participant 112, PLWDMI, female age 26, Dorset)*

This was also the case for bowel cancer screening:

> *"I think it might help if, before it came, if they told me, particularly the bowel one, that it will be coming through the post, that I will be getting this little kit. I think the Doctor should tell their patients" (Participant 041, PLWDMI, female age 64, London)*

Facilitator: Understanding of benefits of screening
Some participants were able to identify benefits of screening such as living longer, being healthier or avoiding disease and seemed motivated to participate in screening programmes:

> *"I know for a fact that the earlier you find out about these things the more chance that the success in beating or fighting these things" (Participant 047, PLWDMI, male age 64 London)*

> *"It's better to find out if you have got it if you found out sooner than later. The sooner you find out the more chances it can be cured" (Participant 032, PLWDMI, female age 43, London)*

> *"They can identify the abnormal or pre-cancerous cells to prevent cancer from developing" (Participant 306, PLWDMI, female age 33, Dorset)*

Facilitator: Encouragement
When participants received encouragement from friends, family or healthcare professionals this appeared to increase their motivation to attend screening.

> *"I know in the past that if I keep putting off going to the doctor, keep putting it off and keep putting it off and my friends then have to encourage me book an appointment" (Participant 015 PLWDMI Female age 56,London)*

> *"I swing between like I said worrying thinking well if I have got cancer I don't care and then the next day I can be really high and really worried because I wished something on myself and then panic and go and get it. But a lot of the time it's my friend and my mum who will push me and say you should get this sorted out, it's probably nothing but just in case" (Participant 307, PLWDMI, female age 35, Dorset)*

> *"Every time I went to my GP and he brought it up I'd say can we do it next time, can we do it next time. He did give me that leeway because he knew it was me and not another one of his patients and so he waited until the time was right for me…he reminded me and said that it's time it needs to be done and I said to him, I explained my fears and said I really, really hate having it done, I really don't want to have it done. He's going I know I understand but it's really important and he is very soothing, he's a very good GP" (Participant 044, PLWDMI, female age 45, London)*

Theme: Motivation to attend
Barriers to cancer screening uptake associated with this theme were: Additional burden; and Mental health symptoms reduce motivation for self-care. Facilitators were: Feeling 'health conscious'; Being anxious to avoid further health problems; and Physical symptoms (e.g. finding a lump).

Barrier: Additional burden
Some Participants said that they did not feel motivated to attend cancer screening because attendance was perceived as an additional burden in their busy and stressful lives. This was particularly the case during periods of ill health:

> *"A letter is just a letter and I've had so many letters recently it's just been washed away with all the other letters and at the moment it's the least of my priorities so whether it's highlighting a priority of it or, yes highlighting the priority of it to me it's the least of my priorities." (Participant 110, PLWDMI, female age 32, Dorset)*

> *"I've only had one smear in my life so I'm overdue, I think it was about 3 or 4 years ago I had my last one. I haven't been because I've just had so much going on in life recently you know you put it off." (Participant 307, PLWDMI, female age 35, Dorset)*

> *"It can be daunting especially when you are feeling so low, when you are feeling low and you get these letters sometimes I feel my head is going to explode" (Participant 015 PLWDMI female age 56, London)*

> *"Sometimes I feel depressed and I'm not in the right frame of mind to go for cancer screening especially as you are supposed to relax so I feel too tense" (Participant 007, PLWDMI, female age 46, London)*

> *"Once you are over 50 most women rightfully in all rights should receive mammograms or breast screening and normal people just get on with it and don't worry about it really and I think they think well the mentally ill should just get over it and get on with things and not complain or find things so hard but I think what they forget is that the mentally ill population some of them do find everyday life quite difficult" (Participant 011, PLWDMI, female age 51, London)*

Barrier: Mental health symptoms reduce motivation for self-care
Several participants stated that when they feel depressed or mentally unwell they struggle to care about themselves:

> *"Sometimes when you are feeling low you don't tend to look after yourself" (Participant 015, PLWDMI, female age 56, London)*

> *"I am not going to be motivated to go anywhere if I don't want to look after myself" (Participant 022 PLWDMI female age 44, London)*

For some, beliefs about their self-worth or the value of their lives may influence their screening choices:

> *"It just seems like nothing is really worth it anyway....it doesn't matter if you were to have it (cancer) because it would do everyone a favour" (Participant 023, PLWDMI, female age 58, London)*

> *"If I were to develop breast cancer or bowel cancer then that for me would be, well that would be the end of my life because my bi-polar is so severe and has been for so long that I would probably be quite relieved if I did develop a form of cancer that was fatal" (Participant 111, PLWDMI, female age 55, Dorset)*

> *"In my darkest moments I've not wished I had, it sounds awful, I've not wished the pain of cancer and I've not wished for the experience that anybody else is going through but what I'm saying is when you in the darkest moments I've sort of wanted something like cancer to kill me."*

> *(Participant 022 PLWDMI female age 44, London)*

> *"I'd have to feel useful again because that's the problem basically I just don't feel I'm any use, I'm just a drain either in here or my CPN's coming round." (Participant 111, PLWDMI, female age 55, Dorset)*

Facilitator: Feeling 'health conscious'
Several participants noted that they were health conscious i.e. they wanted to be healthy and feel well, and this motivated them to attend.

> *"I think it's really important and I think that there should be a lot of awareness raising" (Participant 039, PLWDMI, female age 52, London)*

> *"I tend to think about my health quite holistically so I just try to stay healthy in all respects." (Participant 039, PLWDMI, female age 52 London)*

Having a family history of cancer, in particular, motivated people to attend.

> *"When it comes to cancer and all that I am quite conscious because I have got quite a few people in the family" (Participant 032, PLWDMI, female age 43, London)*

Facilitator: Being anxious to avoid further health problems
Several participants reported attending cancer screening to avoid additional long term health problems which they realised would cause them additional burden:

> *"Because you've already got that mental illness, whatever it could be, and then if you have to deal with breast cancer or cervix cancer or any type of cancer, it's more treatment, more drugs, more doctors, more admissions and another disease that you will have to deal with" (Participant 032, PLWDMI, female age 43, London)*

> *"Well I just think if I have all these problems then I don't want added problems, you know" (Participant 010, PLWDMI, female age 59, London, mammogram)*

Facilitator: Physical symptoms
For some participants, identifying a physical symptom motivated them to access screening. Although cancer testing in response to symptoms is not strictly part of screening and is at odds with the preventative purpose of screening programmes we have retained this as a theme because it reflects the only way some PLWDMI access the screening tests:

> *"I've always said I'll probably die of ignorance because I put things off until I've got symptoms and then it's like oh I'd better get this sorted out now" (Participant 307, PLWDMI, female age 35, Dorset)*

> *"It was only when I felt this big lump that I thought oh shit I'd better do something about it" (Participant 307, PLWDMI female age 35 Dorset)*

> *If I find my body starts malfunctioning in certain ways I would hope that I would sort of say well alright is any of these feelings I'm getting is it any of those things I've spoken to other people about, this cancer that cancer and then I may as I say go to my GP and you know" (Participant 047, PLWDMI male age 64, London)*

Theme: Anticipation of negative or positive experience
Barriers to cancer screening uptake associated with this theme were: Past negative experience; Embarrassment; Traumatising; and Fear of bad news. The only facilitator was: Past positive

experience.

Barrier: Past negative experience
Some participants reported having had previous negative experiences during screening which led to them feeing less inclined to attend in future:

> *"It was all very peculiar and there was a lot of nurses hovering around and I didn't feel very comfortable. Not only that but somebody opened the door when they were there and it was a man so he poked his head around the door. I wanted to complain…" (Participant 109, PLWDMI, female age 52, Dorset, cervical)*
>
> *"It [cervical cytology] was done initially by the nurse at the GP surgery and it was excruciatingly painful. I think that does put me off the whole business of having the screening… the whole experience was quite difficult and frightening and quite painful." (Participant 039, PLWDMI, female age 52, London, cervical)*
>
> *"You have to disconnect yourself from this tugging and the pulling and the squashing and the pinching and the bruising" (Participant 042, PLWDMI, female age 53, London, mammogram)*
>
> *"I would say that's predominantly what puts me off [the unpleasantness of procedure] and I remember feeling as though my breasts had been cut off, I felt very embarrassed to have to go in the waiting room with other people just while they were sort of getting some paperwork together, you weren't even sent anywhere quiet to sit" (Participant 035 PLWDMI female age 53, London, mammogram)*
>
> *"He tried three different sized speculums …it was really painful and it went on for ages and ages and ages …it wasn't a very nice experience to be honest. It didn't put me off I have to say because I know how important they are but it put me off going back to him" (Participant 309, PLWDMI, female age 36, Dorset, cervical)*

Barrier: Embarrassment
Some participants said they found the experience of having screening or of discussing it embarrassing:

> *"I've got nobody to discuss it with for a start, I know I can discuss it with my partner but I'm talking about a male, I didn't have anybody to talk to I was too embarrassed" (Participant 114, PLWDMI, male age 71, Dorset)*
>
> *"It was pretty horrific because you have to lay there, put your legs open and I think that's why I haven't been back really" (Participant 115 PLWDMI female age 35, Dorset)*
>
> *"Very uncomfortable and embarrassing and a little bit unpleasant and a little bit painful" (Participant 011 PLWDMI female age 51, London, cervical)*

Barrier: Traumatising
Some participants reported feeling traumatised by the experience:

> *"Trauma shut me down to the point I couldn't communicate anything" (Participant 035 PLWDMI female age 53, London, mammogram)*
>
> *"It just makes you feel, I don't know as if you've been raped. That's how it feels...You are assaulted" (Participant 015, PLWDMI, female age 56, London, cervical)*
>
> *"There was one smear though that happened that was a trigger to me remembering some*

> *childhood abuse afterwards… But I coped with it and it wasn’t debilitating if you know what I mean, I got over it OK.” (Participant 109, PLWDMI female age 52, Dorset)*

> *“Sometimes maybe if they could have somebody like a mental health worker with you because it’s all very well say for example if you’ve suffered with sexual abuse if you are laying on a bed with your legs spread and them trying to force a speculum in and it’s something that you are very uncomfortable with having somebody there for support would help because it’s all very well the nurse saying oh relax, relax, but when you’ve got a history of abuse it’s something that’s uncomfortable…when I’ve had smear tests in the past I’ve been upset and I’ve cried and they think it’s because I’m in pain and it’s actually because I’m just a bit distressed and feel uncomfortable in that situation” (Participant 306, PLWDMI, female age 52, Dorset)*

Barrier: Fear of bad news
Some PLWDMI expressed that they feared attending screening would lead to a cancer diagnosis. This meant that they sometimes did not attend in order to avoid the experience of anxiety:

> *“Well I’m frightened I suppose, don’t want to know, what I don’t know I don’t worry about so...” (Participant 114, PLWDMI, male age 71, Dorset)*

> *“The last test I had, it had abnormal cells and I was meant to go back but I didn’t…I don’t really want to know.” (Participant 115, PLWDMI, female age 35 Dorset)*

> *“I think I was scared…It’s like burying my head in the sand” (Participant 020, PLWDMI, female age 46, London)*

Facilitator: Past positive experience
Where participants had had positive experiences of screening in the past, they felt more encouraged to attend for future screening:

> *“The clinic … where I went they were amazing there, they were so good and I think as well it helped that they were geared up, the beds were the right type of beds and I found a smear there 100 times better than anywhere else … the conversation was appropriate while it was happening, the supervised member they were very comforting in a way and they also explained every single thing that they were going to do and I think that makes you automatically relax which makes it less painful.” (Participant 309, PLWDMI, female age 36, Dorset)*

> *“I went to an STI clinic as well which was just so much better, I just didn’t feel anything it was just perfect… everyone is just extremely open and it’s the most judgeless place you can go into and very down to business and matter of fact and it’s just what you need… for me now and going forward in the future I would happily go to a sexual health clinic to have it done” (Participant 044, PLWDMI, female age 44, London, cervical)*

Theme: Accommodation of mental health needs by NHS staff and services
Barriers to cancer screening uptake associated with this theme were: Lack of understanding of mental illness in screening professionals; Staff can be rushed; Staff can be rough; Environment aggravates mental health symptoms; and Exclusion from GP registers. A facilitator was: Staff being understanding.

Barrier: Lack of understanding of mental illness in screening professionals
A lack of understanding of mental illness in screening professionals was highlighted:

> *“Last time I went, the lady was laughing because I was shaking but I thought because I told her I was on medication that causes my hands to tremor...she should have been more understanding”*

> *(Participant 003, PLWDMI, female age 45, cervical)*
>
> *"When I've had smear tests in the past I've been upset and I've cried and they think it's because I'm in pain and it's actually because I'm just a bit distressed and feel uncomfortable in that situation and sometimes you can get a bit of a battleaxe nurse who will say come on now it's not that bad and that's not very helpful, not very understanding." (Participant 306, PLWDMI, female age 33, Dorset)*

Barrier: Staff can be rushed
Some Participants reported that they had experienced some screening staff as rushed.

> *"She didn't seem to know what she was doing; it was like she was rushed" (Participant 019, PLWDMI, female age 33, London, cervical)*
>
> *"I feel whenever I go and see my GP for surgery I feel as if they are trying to push you out before you can sit down and really talk to them." (Participant 015, PLWDMI, female age 56, London)*
>
> *"I've never had a rushed appointment in my life compared to the mammogram and it's such a personal thing in such a sensitive painful area it's really left me with quite significant trauma …I'm not happy the way the screening is done I just think, also I remember them being terribly rushed so it was like, as soon as you went in you could see they were anxious and in a panic mood and concentrating on the paper and not even looking at you." (Participant 035 PLWDMI female age 53 cervical)*

Barrier: Staff can be rough
Some participants reported that they had experienced some screening staff as rough.

> *"I didn't realise they pull you about so much…I don't mind going but it's a bit traumatic you know they're pulling, pulling, tugging away at you" (Participant 010, PLWDMI, female age 59, London, mammogram)*
>
> *"I went to run away the lady couldn't do it so she called another colleague in and this lady did the smear but she was actually brutal I felt but maybe in that moment she was brutal but having managed to get the cells she may have saved me a second visit" (Participant 035 PLWDMI female age 53 cervical)*

Although this perception may be due in part to aspects intrinsic to the screening procedures, it may be possible for staff to undertake the procedures in a more gentle way for PLWDMI.

Barrier: Screening environment aggravates mental health symptoms
Managing symptoms during screening or in busy, often noisy, waiting rooms was reported to be a challenge for some participants:

> *"I'm a voice hearer, there are times when you can talk out to the voices so it would be difficult if you were by yourself and you just couldn't control that" (Participant 023, PLWDMI, female age 58)*
>
> *"If I'm at a very low place I may have paranoia so waiting in a room full of other people so paranoia and social anxiety so that's not good, that really isn't good when you are in that place" (Participant 022 PLWDMI female age 44, London)*

Having to wait before being seen can be difficult for some people:

> *"It's the waiting around that I can't stand. I get very impatient and very anxious. Quite a few times I've wanted to just leave because I'm waiting for so long and I can't tolerate it" (Participant 055*

> *PLWDMI female age 32 Dorset)*

Barrier: Exclusion from GP registers
This problem was only raised by participants based in London. A few participants explained that they had been excluded from the practice by their GP, and this led to them missing out on screening invitations if they did not register with another practice. These exclusions typically followed an incident in which the participant had been aggressive towards primary care staff when the participants felt that they weren't always able to control themselves due to their illness and medication.

> *"He (the GP) told me to leave the local area because I wasn't liked around there" (Participant 011, PLWDMI, female age 51, London)*

> *"I asked for my disability living allowance team, physical needs not mental and I said to the GP can you write down my issues and he only wrote about mental and I was very disappointed so I complained…because of my medication it causes aggression as one of the side effects so then I blasted them didn't I" (Participant 003, PLWDMI, female age 45, London)*

> *"I used to go the surgery and say could you see me and they would say we are closing now but somebody after me they'd see so I kicked up such a fuss that in the end they wanted me to go but I thought they did me a favour because I get more quality service where I am now" Participant" (Participant 003, PLWDMI, female age 45, London)*

Facilitator: Staff being understanding
Most PLWDMI talked about how much they valued staff being kind, gentle and reassuring. Expectation of this appeared to motivate people to attend future appointments:

> ”*When you have the actual procedure there's a big difference from someone just being very medical about something in comparison to somebody who is being thoughtful and respecting you and that you are in a situation where it's a bit awkward at times, embarrassing or uncomfortable and it's nice to have a bit of reassurance and being told what's going to happen is, what they are doing next, is really important." (Participant 309, PLWDMI, female age 36, Dorset)*

> *"He's (GP) so accommodating, if I say I really can't get down he will come out or he will send someone out" (Participant 055, PLWDMI, female age 32, Dorset)*

> *"I think if they are nice and quite relaxed talking to you it puts you at ease a lot whereas if you've got someone quite militant you think it's not very nice" (Participant 104, PLWDMI, female age 38, Dorset)*

Facilitator: Staff knowledge of mental illness
The suggestion was made that screening staff should be trained to understand the needs of people with mental illness; this would increase confidence in the PLWDMI to attend screening appointments.

> *"Maybe even to give the people doing the smears some kind of training on how to be more sensitive to people who do suffer with mental illnesses who might be more anxious about the procedure than other people" (Participant 306, PLWDMI, female age 33, Dorset)*

> *"There could be some training with regard to maybe bedside manner that when you get a distressed patient. Maybe she (the GP) was worried that I was going to get aggressive, I wasn't I was just getting very, very distressed, maybe that's why she got fearful and spiky and almost. Her body language changed completely she actually got up and made herself bigger and made herself a bigger presence in the room and then I don't think she knew what she was doing" (Participant*

> *042, PLWDMI, female age 53, London)*

Conversely, some participants expressed concern that if physical health professionals knew they had a mental health diagnosis this could have a negative impact upon their treatment. This may be linked to perceived stigma around mental illness which was also a theme.

> *"I mean if it's a person who is going to take that and it's going to be useful for you, interaction in a positive way then it is important but if that's going to make the interaction more difficult then it's going to be not helpful" (Participant 031, PLWDMI, female age 40, London)*

Theme: Access to screening

Barriers to cancer screening uptake associated with this theme were: Appointment booking; Transport difficulties; Difficulty remembering appointments; Difficulty attending due to health problems; and Taking time off. Facilitators were: Familiar location; and Reminders.

Barrier: Appointment booking

Participants identified difficulty booking appointments due to lack of availability:

> *"In my old surgery it would just be like 'no we don't have any appointments at all.' Even if you've just been in to see the doctor and said he wants to see you tomorrow, they'll be like 'well we don't have any appointments. I'm afraid you'll have to phone in the morning'… Usually with the kids being up and getting off to school it would be really difficult to get that 8.30am appointment" (Participant 115 PLWDMI female age 35 Dorset)*

When booking an appointment, some felt uncomfortable having to give their reason for making the appointment to the receptionist. This may be linked to embarrassment around the screening procedure which was also a theme.

> *"If you want to see the GP you have to specify and they ask you why, you know I can't understand this you know I go to see the GP to get it booked and they ask you why, there might be others there and you have to talk about this." (Participant 047, PLWDMI male age 64, London)*

> *"I mean you know the ringing up making an appointment and you've got the difficulties with very protective reception staff." (Participant 022 PLWDMI female age 44, London)*

Participants disliked booking appointments if they perceived the receptionists as unfriendly:

> *"When I'm booking an appointment sometimes they can be a bit brusque with me." (Participant 048, PLWDMI, female age 49, London)*

Barrier: Transport difficulties

Participants (particularly those in suburban areas of London and those in Dorset) noted that getting to appointments can sometimes be difficult. Reasons stated included public transport being a trigger for anxiety, not having someone available to provide a lift, and difficulty finding a park space. The transportation difficulties were often exacerbated by mental or physical health problems:

> *"I don't drive and with my anxieties I get nervous on public transport and also some days when I'm feeling low and depressed I'm quite tired and it's quite a walk to the bus stop and then it just seems like such a lot of effort. Obviously I'm not working at the moment and taxis are expensive and my partner can't always drive me around" (Participant 306, PLWDMI, female age 33, Dorset)*

> *"Well just making the effort and getting there initially because I did have panic attacks so as I said making the effort in getting there, especially if I had to go on transport" (Participant 305, PLWDMI, female age 62, Dorset)*

> *"So the problem is I'm in here now in X Clinic and I'm trying to get an appointment but what I've been told is that I could get one in Bournemouth or Poole but I don't want to go to Bournemouth or Poole because it means travelling and I'm on water tablets so I prefer not to travel because I need the lavatory frequently. "(Participant 109, PLWDMI, female age 52, Dorset)*

> *"Parking is quite difficult at the hospital because it's quite confusing where to go" (Participant 108, PLWDMI, female age 54, Dorset)*

Barrier: Difficulty remembering appointments

Some Participants reported memory problems which led them to forget to attend appointments:

> *"If I don't put anything in my phone diary I forget so, I forget what I did yesterday so" (Participant 104, PLWDMI, female age 38, Dorset)*

> *"I put everything in my diary and important things have alarms on them as well. I've learnt over the years that depression messes with your memory and it has such an impact on everything that unless I write it down I can't be sure that I said it or that I did it or that I'm going to do it" (Participant 044, PLWDMI, female age 44, London)*

Barrier: Difficulty leaving the house due to mental health problems

Participant's mental health sometimes made it difficult for them to leave the house.

> *"There have been times when I've been very low to the point whereby I don't even want to go out the house and I'm regularly missing appointments and I can't deal with face to face contact" (Participant 042, PLWDMI, female age 53, London)*

> *"When I've been particularly bad and very low I struggle to leave my home so whatever official appointments or non-official appointments I have set up they just go to the wayside" (Participant 044, PLWDMI, female age 44, London)*

> *"Leaving the house because one of my problems is because of being forgetful when I leave the house I will get half way in to town or half way because I stay with my mum in Somerset sometimes, we'll get halfway to Somerset and I'll think shit did I leave a candle burning or incense or have I left the iron on and it was getting to the point where every time I left the house I was like shit I've left something on the house is going to burn down." (Participant 307, PLWDMI female age 35 Dorset)*

> *"If I'm having a bad day, because some days I struggle to leave the house, for example today I'm having a good day so I'm able to get out and about but on a bad day it can be really difficult to get out the door" (Participant 306, PLWDMI, female age 33 Dorset)*

Barrier: Taking time off

Participants identified that where they had work or childcare commitments this could make attending appointments more challenging:

> *"I don't like having to take time off work and also I suppose telling people at work you don't want to have to tell male managers what you are doing." (Participant 039, PLWDMI, female age 52, London)*

> *"Usually I have to make arrangements, childcare arrangements or arrangements for my son to be dropped off at school so that I can get down to the hospital or get to the GP" (Participant 039, PLWDMI, female age 52, London)*

Facilitator: Familiar location

Participants found attending screening easier if the appointment was at a familiar location:

> *"That sort of thing makes a difference where you go if it's a familiar place and if it's a person that you know" (Participant 031, PLWDMI, female age 40, London)*

> *"That is my hospital, that is, where I had all my children, all my medical reports are there" (Participant 004, PLWDMI, female age 51, London, mammogram)*

> *"The second time I had it done it was quite close to where I work in one of the buildings I think linked to [the hospital] but yes so it was more convenient and I could pop down there while I was at work. Those kind of factors I think make a difference, convenience, fitting round work." (Participant 039, PLWDMI, female age 52, London, mammogram)*

Facilitator: Reminders
Many people reported that they found the reminder letters and texts useful as without them they might forget to book or attend appointments but with them participants did not have to worry about remembering when they needed to book or attend their next screening.

> *"I think having a reminder makes it a lot simpler than having to think oh where's my calendar to go write it down because you can always have something going on and you forget" (Participant 003, PLWDMI, female age 45, London)*

Conversely, some participants reported that they did not find the reminder letters useful unless they were supported by conversations with health professionals:

> *"I think for me something a bit more than just a letter that comes through the post. As in like OK let's talk about why you need it and making me feel that I need to have it rather than feeling like well if they are only bothered to send a letter and nobody wants to talk about it then it makes you feel that well obviously I don't really need it" (Participant 110, PLWDMI, female age 32, Dorset)*

> *"I don't think a reminder would make me no I think, well I think if the doctor said or if I had a problem or the doctor said about it I'd probably take more notice of it." (Participant 114, PLWDMI, male age 71, Dorset)*

Others found reminder letters intrusive and found receiving them stressful:

> *"They kept inundating me with letters and that really made me paranoid" (Participant 011, PLWDMI, female age 51, London)*

> *"They wouldn't leave me alone…they kept texting me and I've chosen not to have it and I've told my GP I don't want to have it but they still send the letters, they've probably sent about 5 letters and I just feel like they're really trying to pressure you into it" (Participant 112, PLWDMI, female age 26, Dorset)*

Theme: Relationships with health care staff in general
Barriers to cancer screening were associated with: Feeling like a burden on the health service; Poor relationship with GP; Diagnostic overshadowing; and Stigma of mental illness. Facilitators to cancer screening were associated with: Good relationship with GP; Good relationship with practice nurse; and Continuity of care.

Barrier: Made to feel like a burden on health service
Dissatisfaction with health care staff and services in general, not just in relation to screening, was a strong theme to which many participants contributed. Some participants expressed that they felt that they were a burden on the health service; this seemed to be linked to feeling that they were perceived by health care professionals to be less deserving than others:

> *"I don't darken his door any more than I have to [GP] …I feel that I'm taking up his time, I'm wasting time so I only go if I have to go because it's time for a medication review" (Participant 024 PLWDMI female age 59, London)*

> *"I thought that they weren't actually testing the results properly because I had mental illness or because they didn't like me or my family or whatever in the area where I've been living in in … but they just given me false results and maybe I did have cancer but they weren't telling me the full truth or weren't putting me in the picture about my own health. I just seemed to be another burden on the NHS" (Participant 011, PLWDMI, female age 51, London)*

Barrier: Poor relationship with GP
Some participants described negative or unhelpful interactions with their GP:

> *"I went into the doctors and said look I'm in a really bad way I think I'm going to kill myself, I've got everything I need to do it, and he just said oh try not to do it I'll phone you on Tuesday – this was like a week away – and see how you are. So I just went and did it the next night." (Participant 115, PLWDMI, female age 35 Dorset)*

> *"I got upset when I was trying to talk to her (GP) about this [other more natural treatments for the menopause] and she didn't know what to do. She started slamming drawers and I said I wonder could you be a bit kinder with me because I'm very delicate at the moment and then she started saying you need to get out, I need to see my other patient." (Participant 042, PLWDMI, female age 53, London)*

> *"I very rarely went to the doctors because I just felt as if I had been judged...You feel very exposed for a cervical smear especially when you feel as if you are being judged" (Participant 023, PLWDMI, female age 58, London)*

> *"I feel that he's not really listening (GP) ...when I do book an appointment and they brush me off I just don't want to go back" (Participant 015, PLWDMI, female age 56, London)*

Some participants felt that primary care is very impersonal as there is little continuity of care:

> *"I want to see my GP but I don't even know who that person is until the person turns up" (Participant 047, PLWDMI male age 64, London)*

> *" I've seen the doctor many times but no one has ever mentioned the fact that I've received these letters (cervical cancer screening reminders) and I still haven't had it done so it's obviously just a computer system that automatically sends it out" (Participant 110, PLWDMI, female age 32, Dorset)*

Barrier: Diagnostic overshadowing
Some participants felt that health care professionals were too focused on their mental health problems to take their concerns about their physical health seriously.

> *"I think that's the problem- I'm not taken seriously" (Participant 003, PLWDMI, female age 45, London)*

> *"When I said I had a lump he thought that I was imagining it or gave me the impression that he thought I was imagining it" (Participant 023, PLWDMI, female age 58, London)*

In one participant, this had apparently led to a misdiagnosis.

> *"As soon as the doctor found out that I had mental health problems he said oh all the symptoms*

> *you are experiencing are anxiety and they said get in touch with your psychiatrist, maybe you should go back and get some counselling and I was completely dismissed. He refused to see me and then a week later I had to go to A&E because I'd actually got a water infection that had spread up to my kidneys and that's why I was feeling so unwell because I'd got a fever with it. So it wasn't in my head" (Participant 306, PLWDMI, female age 33, Dorset)*

Barrier: Stigma of mental illness
Some participants feel that health care professionals view them negatively because of their mental health problems.

> *"You feel like you are not important and you don't matter as much as someone without mental health problems" (Participant 306, PLWDMI, female age 33, Dorset)*

> *"I got a referral to a gynaecologist again and on the referral letter at the bottom it had all these mental health related things on the bottom of the letter and it was all about suicide and self-harm and emotional and single personality, and I was like oh my God this person is going think I'm really difficult to deal with and that's going to make him not very nice to me" (Participant 031, PLWDMI, female age 40, London)*

Perceptions of stigma in health care professionals were considered by the participants to reflected wider societal views:

> *"It's not surprising that we die younger because we are not liked" (Participant 011, PLWDMI, female age 51, London)*

> *"I keep my mental health issues quite quiet to be honest because I don't want people judging me because oh she's got schizoaffective disorder, she's a nutter" (Participant 112, PLWDMI, female age 26, Dorset)*

Facilitator: Good relationship with GP
Other participants felt the relationship they had with their GP was important in helping them to take care of their own health:

> *"I think having a good GP surgery like for example they are very sympathetic" (Participant 003, PLWDMI, female age 45, London)*

> *"I think you also build that relationship with, especially with somebody like a GP who you need to trust, it's not just a mechanical interaction it's building up a relationship. "(Participant 019, PLWDMI, female age 33, London)*

Facilitator: Good relationship with practice nurse
Good practice nurses were also mentioned as something that facilitated cancer screening, with participants mentioning the importance of rapport, respect, reassurance, information, and enabling the patient to stop the procedure if she wishes.

> *"It's all down to the nurse and how the nurse is with you…Be friendly and open and you want to know that the nurse does this all the time and for her it's not weird because I think for one the other end it's rather weird, it's a weird thing to do. So unusual, uncomfortable so just to know that the nurse does this all the time and for her it's just run of the mill day to day activity is helpful and for her to develop some sort of rapport with you - discuss the weather, or politics or whatever" (Participant 019, PLWDMI, female age 33, London)*

> *"When you have the actual procedure there's a big difference from someone just being very medical about something in comparison to somebody who is being thoughtful and respecting you*

> *and that you are in a situation where it's a bit awkward at times, embarrassing or uncomfortable and it's nice to have a bit of reassurance and being told what's going to happen is, what they are doing next, is really important." (Participant 309, PLWDMI, female age 36, Dorset)*

> *"The nurse that did it was really good, she explained everything before she did it and again it was the reassurance that if it hurts I'll stop but it won't because it's really quick" (Participant 307, PLWDMI female age 35 Dorset)*

Facilitator: Continuity of care
Continuity of care was described as important; if the PLWDMI had been able to develop a sense of trust in the healthcare professional it was more likely that they would attend for healthcare:

> *"Continuity would be helpful" (Participant 019, PLWDMI, female age 33, London)*

> *"I know it's not possible to always have the same people but I think a little bit of familiarity knowing what you are going to expect is a big pull in itself" (Participant 035, PLWDMI, female age 52, London)*

> *"I mean for me there's a nurse at the GP …she's really nice and I've known her for a long time and she's the sort of person who makes, and I've been there before when I've hurt myself and stuff and she's been really nice about that and she hasn't been nasty, she's been sympathetic and helped me sort things out so I think she's a nice person so an experience like that is better with someone who you know already and who is sensitive." (Participant 031, PLWDMI, female age 40, London)*

> *"Emotionally I mean I always go back to the same nurse at the GP" (Participant 039, PLWDMI, female age 52 London)*

Screening professionals

Four themes were identified: Approaches to meeting complex needs; Attitude to PLWDMI; Communication skills; and Integrated care. These themes, the barriers and facilitators relating to the themes, and whether there was support for the barriers and facilitators across the different types of screening is shown in Table 6.

Theme: Approaches to meeting complex needs
Barriers to cancer screening were associated with: Lack of knowledge of SMI; and Lack of time. One facilitator was identified: Understanding of emotional and practical barriers to screening uptake for PLWDMI.

Barrier: Lack of knowledge of SMI
More than one screening professional confused mental illness with learning difficulties:

> *"I think it's easy to get confused between people who have got mental illness and people who have got mental disability" (Participant 059, Practice Nurse, female, London)*

> *"If we know that a client obviously comes under the mental health act we do have another leaflet which is much more picture driven to try and give a better understanding." (Participant 053 managerial staff breast cancer screening unit, female, London)*

In the above quote, the participant was referring to a leaflet designed for people with learning disabilities. Though some PLWDMI may have impaired literacy or cognitive skills, it wasn't clear if the professional would assess need on an individual level.

Some screening staff reported having received limited training on mental illness:

> *"No we've never done any training on women that could possibly come with mental illness, I think it's something that you are expected to pick up on the job" (Participant 056 Mammographer, female, London)*

> *"Obviously again when something like that happens in clinic the radiographer doesn't know what the condition is, they might know that the lady is upset and they might know that she has got a carer but they don't, and again they're not psychiatrists so they don't know and understand whether this is a permanent condition, is it something that with medication is treatable so all we can do it capture the information that is at the time but obviously appreciate that sometimes when the lady comes back the next time it maybe a completely different scenario" (Participant 054 managerial staff (breast cancer screening unit), female, London)*

Barrier: Lack of time
Practice nurses and breast screening staff suggested that because appointment times are limited, it would be helpful to know in advance if a patient would require service adaptation:

> *"On a high pressure work day if you've got a very busy clinic it can just be very hard for the clients because we can't give them as much time as we want or that they might necessarily need because we've got to see X amount of people and you don't want to keep other people in the waiting room waiting particularly with some of our satellite units as well like the little vans that we use there's only a finite amount of space" (Participant 057, Mammographer, female, London)*

> "G*enerally speaking when I do screening I do know the history of the person, how much regard I've taken that into account or how much I've really taken that on board would depend on how much of a rush I'm in because it's not obviously normally overtly relevant to the fact that somebody needs to have a cervical screen whether or not they've got mental illness*" *(Participant 059, Practice Nurse, female, London)*

> *"Sometimes it's an explanation, sometimes it's them just wanting to stop, sometimes they just want to stop in between, they don't want to talk, some say 'it's very painful, one minute I need to sit down' and you just think oh, obviously me being anxious knowing that I've got another patient in 6 minutes I try and do it as fast as I can" (Participant 056 Mammographer, female, London)*

> *"With any patient you might not have time to deal with anything other than what the consultation is about…" (Participant 060, General Practitioner, male, Oxfordshire)*

Facilitator: Understanding of emotional and practical barriers to screening uptake for PLWDMI
Several screening professionals demonstrated awareness of the barriers PLWDMI may face when attending screening and their empathy was evident:

> *"A long wait here, the waiting room is chaotic and it's not a particularly nice environment and you have to be fairly organised to come to a clinic like this to get a ticket and so the access isn't really that easy for people" (Participant 013, Sexual Health Nurse, female, London)*

> *"A lot of people feel that they've got too much in their lives to bother with screening and obviously with mental health they have other issues and actually screening is not that important" (Participant 054 managerial staff (breast cancer screening unit), female, London)*

> *"She had a problem being undressed in front of a stranger which is obviously quite difficult when you are doing a mammogram so I asked how I could help her with that. She said she wasn't sure we'd just have to get on with it, she did want to attend the screening, she did realise the reasons why and I suggested to her would you like me to turn the lights off and she went yes actually I*

> *would. So we did a mammogram with no lights on, in a completely dark room which was a little bit strange but we got on with it." (Participant 057, Mammographer, female, London)*
>
> *"If someone finds it upsetting again you would get a feel of the person and make sure, well I'd want to make sure I was sensitive to that and I would think is it so upsetting that it's going to be worse for her to have this smear and what are her risks" (Participant 051, Practice Nurse, female, Kent)*
>
> *"In my role of reminding them that they are overdue to have this done I think the only thing I would do differently is that I would, as I would with any patient, try to tailor my advice to their own needs. In that sense it might take me longer to explain to someone who had those difficulties why this was important and why it should be a priority for them... So I think it is important that we recognise that some people need more information, reassurance, advice and general input in order to adhere to the programme." (Participant 060, General Practitioner, male, Oxfordshire, cervical)*
>
> *"I think we have to respond to the fact that people with severe mental illness have different needs in terms of their information needs and the way we communicate all the issues. We have to respond to that not by allowing the issue to be forgotten about or deprioritised but by making sure that they get what they need which may be longer appointments or more frequent appointments or other sources of material, information or material." (Participant 060, General Practitioner, male, Oxfordshire)*

Theme: Attitude to PLWDMI
One barrier was identified: Find complex patients difficult. One facilitator was identified: Staff motivated to encourage screening for all groups.

Barrier: Find complex patients difficult
The language used by one screening professional indicated a negative attitude towards PLWDMI, they clearly struggled to understand the patient's point of view, that they were aware of this is important.

> *"Sometimes it could just be them being very difficult from the start, being sometimes even aggressive or rude… some women are quite the opposite they seem very needy and they need to sit down and can I have some more time and it's just a mammogram obviously to me" (Participant 056, Mammographer, female, London)*

In primary care, staff are prompted to offer tests to a patient via digital reminders or 'flags' which appear when a patient's notes are accessed. Patients with complex needs may trigger several flags and dealing with competing needs can be challenging for staff within a 10 minute consultation:

> *"If you've got five or six reminders it's unlikely you are going to cover all of them in 10 minutes particularly as none of them are actually the reason why this consultation was arranged" (Participant 060, General Practitioner, male, Oxfordshire)*

Facilitator: Staff motivated to encourage screening for all groups
All staff demonstrated that they were highly motivated to promote cancer screening:

> *"It should be something that is promoted because certainly cervical screening has a financial incentive for general practice so it is in their interest to encourage as many women on their list to have cervical screening"(Participant 002, Sexual Health Nurse, female, London)*
>
> *"I think it is really important for us to promote breast screening to the wider population especially for ladies who might not be able to be self-aware of the different issues that go on with the*

> *breasts" (Participant 058, Mammographer, female, London)*

Theme: Communication skills
One barrier identified was: Communication skills training not available to all. Facilitators were: Importance of good communication skills recognised; and Confidence to screen anyone is associated with good communication skills

Barrier: Communication skills training not available to all
One participant identified that not all members of the team have access to communication skills training. Each staff member will differ therefore in their ability to communicate with clients when under pressure.

> *"I think communication course is very important… we're not all just radiographers some of my colleagues are assistant practitioners and the radiographers are supported in 'OK we'll let you go on eventually to the communication course' but APs are not given that right even though they do screen these women and they may get a women who could be mentally unwell" (Participant 056, Mammographer, female, London)*

> *"If they are stressed and tense it's very difficult to get them to cooperate because the machine we have is quite awkward, there is a lot of leaning and lifting of arms and small movements so it's a stress, sometimes they are not listening and it's difficult to convey what you want them to do" (Participant 058, Mammographer, female, London)*

Facilitator: Importance of good communication skills recognised
All types of screening staff were aware of the importance of good communication in supporting a positive screening experience:

> *"I think once again just giving them time and allowing them to tell you what their concerns are. Giving them that opportunity not just bulldozing them in to something and once again reiterating they don't have to have this done, if it's making them feel uncomfortable they've always got the opportunity to say stop either during the procedure or if they want to just not go ahead with the procedure then that's fine" (Participant 057, Mammographer, female, London)*

> *" I think being able to listen to what they want so how they are feeling (is important" (Participant 058, Mammographer, female, London)*

> *"It's very important with everyone but it's obviously probably that little bit more important to be really clear with people about the procedure, full information and support with any questions or queries and a very, very important thing with any intimate examination that the individual feels in control" (Participant 002, Sexual Health Nurse, female, London)*

Facilitator: Confidence to screen anyone is associated with good communication skills
Where staff felt they had good communication skills, they felt confident to provide screening for all patient groups:

> *"I feel quite confident that I've met a lot of different people, different personalities and it helps you to adapt in different situations" (Participant 058, Mammographer, female, London)*

Theme: Integrated care
Barriers identified were: No means of knowing patient needs in advance; and Computer systems not linked across healthcare settings. Identified facilitators were: Practice nurses can access patient record; and Reactive measures in place if notice given.

Barrier: No means of knowing patient needs in advance

Breast screening and sexual health clinic staff identified that as they do not have access to patient records they are not aware of a patient's need prior to appointments. This made it difficult for them to make the necessary adjustments to their service.

> *"There is no way of knowing, so sometimes you are just presented by a situation that you were not prepared for at all…If you don't know about any mental disability then you haven't accommodated have you, you assume she's well, just because you can't see it physically you are assuming she's well" (Participant 056, Mammographer, female, London)*

> *"So we don't get very much information from the GP's practice it's pretty much the client's name, address, phone number and anything else that we feel we need we'll ask the client there and then but that's really all we get from a GP's practice...they wouldn't tell us anything about the patient's mental health and they wouldn't tell us about any other medical condition that they would have which is sometimes confusing for patients and clients because they say but you know all of this and we're like well no we don't, we don't actually really get a great deal of information " (Participant 057, Mammographer, female, London)*

Barrier: Computer systems not linked across healthcare settings

Separate computer systems between services can make information sharing challenging:

> *"If they get the letter from the NHS agency they may not know that they have a mental illness so it makes it harder because they don't always have access to records" (Participant 051, Practice Nurse, female, London (Kent))*

> *"We get informed if somebody hasn't turned up for one but that would be as a letter that would end up in their notes rather than a screen reminder message which is linked to the actual system" (Participant 060, General Practitioner, male, Oxfordshire)*

> *"In a GP practice they're in a slightly better position because they've got the information so they can check on the records and say well actually you had it two weeks ago or we've got a result from three months ago because our records are completely confidential to any other service, this is the sexual health service we can't do that so if we can't actually find that information out maybe we have to make a judgement to go ahead and do it." (Participant 002, Sexual Health Nurse, female, London)*

Facilitator: Practice nurses can access patient record

In GP practices a note of screening attendance or non-attendance can be made by 'flagging' it on the computer system: breast and bowel screening services send this information to GP practices via letter. Practice nurses conducting cervical cancer screening tests can then see this information when a patient attends for any appointment.

> *"How they can help is when they get a DNA notification from us to flag that up on their system then the next time they get access to the woman whether it be because she comes in for an appointment or pops into see the nurse to then maybe say 'did you receive your appointment?' and then it opens up the channel about why they haven't attended. So it's actually using the people that have got the access" (Participant 054, managerial staff (breast cancer screening unit), female, London)*

> *"So there is something that primary care can do to alert people to their screening programme, and if they don't attend all of these notes will be flagged, they will all be identified or the notes will be flagged so that opportunistically when the people come in for their medication or for their prescription that it's been asked you didn't attend your mammogram, your screening for breast cancer, I wonder why not" (Participant 016, managerial staff, breast cancer screening unit, female,*

> *London)*

Facilitator: Reactive measures in place if notice given
If breast screening professionals or, in some practices, practice nurses, know in advance that a patient has additional needs, they are able to provide a longer appointment and make adjustments to staffing arrangements. For instance, if the patient would like to see a female member of staff this can be arranged in both breast and cervical cancer screening settings.

> *"I think sometimes telling us prior to the examination might be helpful because then we can be prepared, for example if you've got somebody with quite a severe physical difficulty it's helpful to have two radiographers in the x-ray room. If you have somebody who might have violent or aggressive tendencies it's safer to have two radiographers in there… Also to give them more time as we mentioned five minutes is tiny so if you know that you can accommodate them by giving them a longer appointment then it's a lot easier" (Participant 057, Mammographer, female, London)*

> *"The practice would be very understanding if I gave a double appointment to someone because they know that I wouldn't do that without good reason and I'd want other nurses to do the same. But they may not know in advance that they'd need a double appointment so that perhaps would be good if they did" (Participant 060, General Practitioner, male, Oxfordshire)*

> *"Well definitely hopefully give them more time, be prepared myself in the sense that OK this is the next lady I need to make sure, you just prepare yourself mentally as well for us I need to be a bit more patient, I need to get the room ready, explain things. It's almost like you are able to prepare yourself to be at your best as well as the clinician, maybe prepare the paper to hand it to them, maybe if you need to show them drawings. You will be able to deal with it I think better if you were expecting something" (Participant 056, Mammographer, female, London)*

> *"If we were aware that there could be an issue then at least everybody that is concerned and that will have hands on are aware of the situation. I think that that actually facilitates for a better experience because otherwise we must admit that when we do get a high uptake it is a conveyor process and obviously that's not conducive to that sort of client." (Participant 054, managerial staff (breast cancer screening unit), female, London)*

Conversely sexual health nurses reported that due to the flexible nature of their clinic appointments they are able to provide longer appointments.

> *"So I think people with severe mental illness certainly … the consultation may be longer, you have to be able to have the time which I know can be a problem sometimes in GP practices you are quite limited with time, the service I use we don't have a time limit so … we could see someone for 45 minutes if that person needed that time" (Participant 002, Sexual Health Nurse, female, London)*

Mental health professionals

Three themes were identified: Knowledge and confidence to promote screening; Integrated care; Health service delivery factors. These themes, the barriers and facilitators relating to the themes, and whether there was support for the barriers and facilitators across the different types of screening is shown in Table 7.

Theme: Knowledge and confidence to promote screening
The barriers identified were: Lack of knowledge of screening programme and procedures; Promotion of cancer screening not prioritised; and Lack of a structured behaviour change approach. The facilitators identified were: Health promotion seen as their role; Aware that PLWDMI are at risk of

cancer; and Diagnostic overshadowing known to be a problem.

Barrier: Lack of knowledge of screening programme and procedures
Most mental healthcare professionals interviewed said that their knowledge of the National Cancer Screening Programme was poor and that they were unclear how to promote it.

> *"One of our questions we were asking people which is on RIO [NHS electronic patient record system] is something about, I think it's towards the men… have you gone for your cancer checks for bowels or whatever and we have no idea what age you are meant to do that, it's not on there at all… so it's clarity really as to what screening is available for people so that we do know what to be promoting" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

> *"One of the outcomes for me is I think I need to look at the details of cancer screening programmes so that I'm really clear so that I can support how often people should go for what and how and when and what are the indicators and how would they do that and where would they access that" (Participant 038, Occupational Therapist, female, London)*

> *"To be honest I don't know much at all... (The national cancer screening programme), it doesn't figure in my day to day work at all really" (Participant 050, Psychiatrist, male, London)*

Some mental health professionals associated the need for screening with the identification of a symptom rather than as an illness prevention intervention.

> *"If they raise a symptom then definitely they would be prioritised to be investigated …if they haven't mentioned it then no one would know" (Participant 037, Occupational Therapist, female, London)*

Mental health professionals sometimes did not know where to access information:

> *"It's not easy at the moment to promote it because we don't, as clinicians, we don't necessarily know where we have to go to get the information to promote it" (Participant 302, Mental Health Nurse, female, Dorset)*

Some staff said they would welcome training.

> *"I think we should have the opportunity for people to come in and give us lectures on what to expect or what to tell patients or what to make them aware of." (Participant 029, Mental Health Nurse, female, London)*

Barrier: Promotion of cancer screening not prioritised.
Participants commonly stated that the management of mental health problems and their treatment was their primary concern, leaving little room for attention to cancer screening needs.

> *"Our priority is, you know, engagement, stabilisation and not cancer screening" (Participant 017, Mental Health Nurse, male, London)*

> *"Cancer risk is rife amongst the population anyway and there is quite an awareness about it anyway but with this group it's so easy to overlook that because there are so many other more apparent problems that they come into contact with us with so it wouldn't always be at the forefront of our mind" (Participant 046, Student Mental Health Nurse, male, London)*

> *"We probably haven't focused on at all the cancer side, we've been more like you say wrapped up with the metabolic syndrome and looking at heart disease and diabetes and not all that side of it*

> *really" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

It was also felt that patients may not prioritise cancer screening.

> *"The sad truth is that people tend to be more concerned about the medication that they are obliged to take for their mental health issues than they are about lifestyle, diet, things like that" (Participant 021, Social Worker, female, London)*

Some staff reported engaging in health promotion, but this did not usually include discussion of cancer screening:

> *"We talk about the relationship with GP, ongoing physical health problems, any previous diagnosed conditions, medication for physical health, when they last saw the dentist, nutrition screen, optician things like that, lifestyle issues and obviously we work alongside other services to look at sexually transmitted diseases and things like that but in terms of cancer screening I'd say that my knowledge is quite limited" (Participant 040, Mental Health Nurse, female, London)*

In the absence of guidelines or policy, clinical practice may vary between individuals in terms of whether or not cancer screening is promoted.

> *"I think it (promotion of cancer screening) varies from person to person, some people maybe aren't as keen and don't think it is that important" (Participant 101, Occupational Therapist, female, Dorset)*

> *"As a team it had been hit and miss especially since multidisciplinary and some of the team members are social workers and they would say well we don't know what to look for or what questions to ask or they weren't comfortable with doing patients weight and stuff like that" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

Barrier: Lack of a structured behaviour change approach

None of the professionals talked about using evidence based behaviour change techniques in terms of cancer screening promotion or health promotion in general. Rather, discussions with patients around physical health were described as informal and advice based*:*

> *"They all talk about their physical health and stuff like that so sometimes, like I said, I do find myself talking about health issues, what they can do and how they're feeling; period pains, headaches, all sorts." (Participant 030 vocational worker, female, London)*

> *"My job as an OT is looking at people's routines and their lifestyle and if they are drug taking and unhealthily eating and all of those things then I would definitely talk to them about all of those things and what they're doing with their time. Just basically all areas of their life really but it's not really like in a formal way it's more woven into just normal conversation." (Participant 037, Occupational Therapist, female, London)*

One participant felt this current approach may have disempowered patients.

> ***"****I think also because we've done so much for these patients as well maybe we've deskilled them in some way for taking responsibility for their own healthcare needs as well so they wait for us to do it for them" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

Facilitator: Health promotion seen as their role

Most mental health professionals interviewed agreed that health promotion was an important part of their role and that it was important. This indicates that they would be motivated to promote cancer screening uptake.

> “*Our remit is to consider someone’s physical health as much as their mental health but our remit I guess is also about promoting positive engagement with health services which that could be part of*” *(Participant 018, Mental Health Nurse, female, London)*

> “*You are always thinking about someone’s physical health care because of the medications that they are on but you are also thinking about their physical health care because clearly that is going to affect their mental health so it is important*” *(Participant 050, psychiatrist, male, London)*

Some, mostly community staff, also considered that providing support to attend physical health appointments, such as for cancer screening, was part of their role.

> *“Sometimes it’s as simple as literally getting them there on time and to the right place so it can be a very practical thing. I think sometimes it can be a language thing they just need a bit of extra support to understand... it might be just they want somebody else with them so that they are clear about what has been discussed or agreed by the doctor.” (Participant 043, Mental Health Nurse, male, London)*

Facilitator: Aware that PLWDMI are at risk of cancer
Mental health professionals were aware of the increased risks associated with cancer in PLWDMI and the injustice of this; this could motivate them to want to promote cancer screening uptake.

> *“We know that the mortality rates of being with psychosis is 20 years less thereabouts than people without … that’s appalling really and it is COPD and cancers and diabetes that are the causes of that high mortality rather than schizophrenia, people don’t die from schizophrenia they die from lung cancer, breast cancer, cervical cancer, airways disease, heart attacks, things like that” (Participant 038, Occupational Therapist, female, London)*

> *“Cancer is roundabout the third leading cause of death within the population, it not only causes death it causes disability, suffering, reduced quality of life and angst for carers and loved ones and relatives as well as the individual involved so there’s a real priority in looking at early identification intervention and particularly within people with severe mental illnesses who for a range of factors are at a greatly increased risk” (Participant 005, Senior Lecturer in Mental Health & Mental Health Nurse, female, London)*

> *“I would imagine the patients we look after anyway have a lifespan that is 15, maybe 20 years sometimes less than the average person and sometimes that is due to medication and I imagine they probably don’t go to as many physical health checks up as maybe other people do” (Participant 103, Mental Health Nurse, male, Dorset)*

> *“I’m aware that people with severe mental illness have an increased risk of dying from cancer” (Participant 103, Mental Health Nurse, male, Dorset)*

Facilitator: Diagnostic overshadowing known to be a problem
Mental health professionals were also aware of the dangers of diagnostic overshadowing.

> *“If there is primary diagnosis of depression or psychosis that gets sort of, I think GP’s get influenced by that and if somebody starts coming in saying I’ve got physical health problems they think oh it’s caused by the psychosis or that’s caused by the depression” (Participant 028, Mental Health Nurse, male, London)*

> *“Part of it may be to do with GP’s having difficulty perhaps understanding or interpreting*

> *someone's presentation and not recognising a physical health concern or not focusing on physical health concern and wanting to focus on mental health concern when it isn't what the person has come for" (Participant 017, Mental Health Nurse, male, London)*

> *"If there is primary diagnosis of depression or psychosis that gets sort of, I think GP's get influenced by that and if somebody starts coming in saying I've got physical health problems they think oh it's caused by the psychosis or that's caused by the depression" (Participant 028, Mental Health Nurse, male, London)*

> *"I think part of it may be to do with GP's having difficulty perhaps understanding or interpreting someone's presentation and not recognising a physical health concern or not focusing on physical health concern and wanting to focus on mental health concern when it isn't what the person has come for. So it might be that the GP, yes doesn't strike a balance I suppose between the two." (Participant 018, Mental Health Nurse, female, London)*

This awareness prompted staff to pay attention to physical health problems.

> *"I got the impression from the literature that perhaps there's maybe an assumption that mental health patients are often sort of they think oh that's probably their mental health but I don't think they do do that on the ward that I work on. They will examine things even if they appear to be psychological in origin" (Participant 037, Occupational Therapist, female, London)*

Theme: Integrated care

Barriers identified were: Lack of collaboration between healthcare services; Lack of physical health expertise; Stigma of mental illness. A facilitator identified was: Understanding of emotional and practical barriers to screening uptake for PLWDMI.

Barrier: Lack of collaboration between healthcare services

Lack of collaboration between different agencies involved in caring for PLWDMI (i.e. primary and secondary care mental health services, primary care and cancer screening services) was proposed as a barrier to cancer screening promotion.

> *"Often I find that a lot of the feedback between GPs and secondary care is very one way…the only way you'll get feedback from the GP is if you really chase them up" (Participant 043 Mental Health Nurse, male, London)*

Participants explained it was often difficult to liaise with other services due to busy working environments and different working hours.

> *"Sometimes I'll ring a GP and they'll say there is no one available and they'll call me back and it will be 7pm at night" (Participant 050 Psychiatrist, male, London)*

Difficulties in inter-professional communication arise due to different priorities and use of language.

> *"As a nurse or a social work say they are having to liaise with the GPs sometimes it's harder for them to get their points across or their concerns across" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

A particular, well recognised problem is that computer systems are not integrated across services so patient records are not always accessible.

> *"It would just be so much easier if there was more of a centralised system whereby we could get access to more information" (Participant 050 Psychiatrist, male, London)*

> *"We don't have the GP summary or an up to date one and so it just ends making quite a lot of extra work trying to get hold of this information" (Participant 050 Psychiatrist, male, London)*

Mental health professionals are, therefore, unable to find out when a patient is due to attend for cancer screening unless the patient tells them.

> *"I think that's probably more difficult for us sometimes because we use different computer programmes … sometimes knowing when all our patients have appointments can be a bit difficult for us unless we get a letter or they come with a letter sometimes we don't always know what they are due" (Participant 103, Mental Health Nurse, male, Dorset)*

Barrier: Lack of physical health expertise
Mental health professionals may not feel competent in managing or promoting physical health; this may be due to lack of training.

> *"I don't want to over generalise but I think specialist mental health settings the majority of staff are focused specifically on mental health issues and in general terms their training reflects this" (Participant 005, Senior Lecturer in Mental Health & Mental Health Nurse, female, London)*

> *"Generally I think people's mental health nurses' confidence in addressing physical health issues is probably quite low unless you have had particular experiences that have led you to develop confidence ... it feels a bit beyond our comfort zone" (Participant 018, Mental Health Nurse, female, London)*

Though aware of policies promoting holistic care, staff nevertheless tended to distinguish between mental and physical healthcare.

> *"I know that people in mental health services we're really pushing to try and get people to join up the physical and mental health side of things and I think often we tend to focus just on our specialism at the expense of the physical health in general." (Participant 021, Social Worker, female, London)*

Barrier: Stigma of mental illness
Mental health professionals believed that other professionals may dislike working with people with mental illness.

> *"There's the general attitude towards mental illness in primary care… for example, forensic histories and mental, quite severe and enduring anti-social histories are best avoided" (Participant 017, Mental Health Nurse, male, London)*

> *"Somebody with a mental health diagnosis was saying they went to their GP because they had a chest infection and the receptionist said to them when they were checking them in said 'oh you people are always coming to the GP, you are always taking up all of our time, and you spend hours in there'" (Participant 018, Mental Health Nurse, female, London)*

> *"Some GPs are also quite harsh, when I was a CPN myself I had quite a few clients who got struck off by the GP because either they are perceived as not following the rules or they are perceived as rude to the receptionists" (Participant 008, NIHR Research Fellow & Honorary Consultant Nurse, female, London)*

They felt that patients were aware of this.

> *"Sometimes they've had bad experiences with GPs. They find the GPs don't understand about mental health particularly well so they feel that the GP has just dismissed them whenever they try and complain about a physical problem" (Participant 028, Mental Health Nurse, male, London)*

Facilitator: Understanding of emotional and practical barriers to screening uptake for PLWDMI
Mental health professionals were able to identify a number of barriers to screening uptake for PLWDMI, which the PLWDMI had also identified. Awareness of this may motivate staff to help promote cancer screening uptake, though there was no evidence of this.

> *"I suppose attending these appointments, sometimes reading ... the appointment date and time and what it's for, obviously their mental state as well and yes money, and their motivation or actually not realising how important it actually is, not having the knowledge" (Participant 040, Mental Health Nurse, female, London)*

> *"Think about negative symptoms of schizophrenia and chaotic lifestyle in and out of hospital, drugs and alcohol, depression, all these things and plus I guess if they don't go to the GP and they see us and we're not very good at it because we don't really know much about it" (Participant 050, Psychiatrist, male, London)*

> *"I think it's for some who don't particularly trust health professionals or don't particularly trust health services then ... they may be quite dismissive of or quite reluctant to engage with processing that kind of information" (Participant 018, Mental Health Nurse, female, London)*

> *"Our patients complain about waiting times to see a GP. A lot of them are quite anxious sat in a waiting room." (Participant 017, Mental Health Nurse, male, London)*

Theme: Health service delivery factors
Barriers identified were: Cancer screening promotion not their responsibility; Patient's mental state; and Lack of resources. Facilitators were: Willingness to promote screening; and Screening promotion could be included when considering other health risks.

Barrier: Cancer screening promotion not their responsibility.
No mental health professional specified that promotion of cancer screening was explicitly part of their role. They felt that the GP or another professional was responsible.

> *"This is something I would have thought their GP would have or maybe assertive outreach somebody who works more long term with the patients" (Participant 106 Support Worker, male, Dorset)*

> *"The priority is really for GPs to be on top of that with breast screening for individuals, making sure that women are undergoing their cervical screening and sending letters out and maybe GPs because we attend the practice meetings like liaise with us and say do you know what Mrs So & So hasn't been in for a while and we would then potentially say would you like some help to go up to the GP surgery, are you anxious about anything, is there anything we can do to support you so that you can access primary care." (Participant 301, Community Support Worker, female, Dorset)*

Some expressed concern that taking on this role would be inappropriate or unmanageable.

> *"There is a balance to be struck between what is part of your role because it's for the benefit of the service user and what is, there is a bit of a danger that if you as a mental health professional take on a lot of the work that otherwise might be done by GP or a primary care service then it's slightly, it takes away the responsibility from the primary care service" (Participant 018, Mental Health Nurse, female, London)*

> "*I suppose there's that kind of assumption whose role and responsibility it is maybe? Is this something that the GP should be advocating, is it something that the GP should be monitoring or is it that this should be everyone's responsibility and maybe there's obviously we've got KPIs, we've got key performance indicators that nurses have to and I suppose healthcare professionals have to meet and sometimes when it's not on a screening it won't be asked. "(Participant 040, Mental Health Nurse, female, London)*

Barrier: Patients' mental state
Staff in acute settings, such psychiatric intensive care units, felt that their patients were too mentally unwell for promotion of cancer screening to be a priority; perhaps because people would lack capacity to understand.

> ***"****I think if somebody is suffering from some of the anxiety syndromes, severe anxiety again you'd need to be mindful of how any additional stress would affect them physically and you would have to balance that against the benefits of actually trying to persuade them to go through the screening process "(Participant 302, Mental Health Nurse, female, Dorset)*
>
> *"I think we've got to get this in the right area there is no point somebody like me doing it in PICU it's got to come from home treatment teams and CPN [Community Psychiatric Nurse]. The areas where unless you actually say to them you have to you write it on a care plan and they have to book it because that's actually the only way you'll get it done" (Participant 001, Lecturer in Mental Health and Consultant Mental Health Nurse, female, London)*
>
> *"This is an acute treatment place where patients are generally here for 72 hours, some are long term but very rarely. We deal and specify straight within the mental health and it's such a quick turnover if they did have, if we started the role of screening we wouldn't be there to follow it through" (Participant 106 Support Worker, male, Dorset)*
>
> *"I think if someone is acutely paranoid, acutely ill, very paranoid, very disturbed that's not the time to approach them around screening." (Participant 038, Occupational Therapist, female, London)*

Barrier: Lack of resources
Participants were concerned about managing the extra workload they thought might be associated with promoting cancer screening.

> *"It's finding the opportunity and having the time" (Participant 001, Lecturer in Mental Health and Consultant Mental Health Nurse, female, London)*
>
> *"I suppose cost wise then they are going to be taking less resources out of the system later on but the problem is later on is many years on and so it's very hard then to get those costings and prove how much money you are saving because it's not everybody is just so interested with the here and the now aren't they, not what you are going to save in 10 years or 15/20 years time" (Participant 308, Mental Health Nurse Practitioner, female, Dorset)*

They worried that extra resources may be needed and were not available.

> *"How we mobilise, where does that resource come from" (Participant 038, Occupational Therapist, female, London)*

Facilitator: Willingness to promote screening
Despite the barriers identified, some mental health professionals nevertheless demonstrated a willingness to promote cancer screening with their service users:

> *"I think we should be promoting screening for cancer definitely it's just we maybe need a bit more education about when and who we should be promoting it for" (Participant 103, Mental Health*

> *Nurse, male, Dorset)*

Some mental health professionals mentioned that our interview had raised their awareness and that this had encouraged them to take more of a role in cancer screening promotion:

> *"I mean I haven't had anybody coming in to speak to us or have even questioned us this is the first time ever so I think it's good, what you are doing is good…we are becoming more aware of what we should be doing really" (Participant 029, Mental Health Nurse, female, London)*

> *"I deliberately didn't look anything up in anticipation of this interview but actually one of the outcomes for me is I think I need to look at the details of cancer screening programmes so that I'm really clear so that I can support how often people should go for what and how and when and what are the indicators and how would they do that and where would they access that." (Participant 038, Occupational Therapist, female, London)*

Facilitator: Cancer screening promotion included in routine health promotion
Some mental health professionals highlighted the importance of promoting the annual physical health check. The annual physical health check is incentivised in primary care for people who are taking certain medications; this check includes promotion of cancer screening.

> *"With promoting cancer screening it would really be something that we would be looking at when we get all the initial assessment information together and promoting annual physical reviews with GPs so because we know that there tends to be a problem with people with enduring mental health problems keeping their annual physical review appointments that's something that we would help to facilitate and provide support and discussion on" (Participant 304, Mental Health Nurse, female, Dorset)*

> *"I suppose it should be included in their care plan or when they have their physical health assessment, it should be incorporated to it whether they want to have this check and that check and they usually tick it themselves so it's good" (Participant 052, Mental Health Student Nurse, female, London)*

Other participants discussed cancer screening as part of the physical health assessment undertaken when a new patient is admitted to a mental health ward.

> *"I think if maybe cancer screening that is part of the physical health assessment [for inpatients] that needs to be included; it's not at the moment so maybe we need to open up that discussion as to how we include asking those questions" (Participant 302, Mental Health Nurse, female, Dorset)*

Some participants reported that their services use standardised tools or checklists as part of assessments to identify whether patients have any health needs. This was in order to help them meet CQUIN targets.

> *"We pulled stuff from RIO, stuff from the Rethink physical health check and stuff to tie in with the CQUIN requirements we have so it all fits in to about a three page health assessment" (Participant 105, Nursing Assistant, male, Dorset)*

> *"This is the one we should do which is the physical health check devised by Rethink and a few professionals that we actually know and I used to work with, so everyone in our Trust who is on CPA will have that physical health check that includes blood pressure, weight, all the calculation of the BMI, give some basic information for example if you are a woman the CPN should talk to about you need to arrange for a Pap explain a little bit why you need a Pap etc.etc" (Participant 008, NIHR Research Fellow & Honorary Consultant Nurse, female, London)*

Not all participants were aware that tools such as The Rethink Physical health check tool (Rethink Mental Illness 2014) refer to cancer screening, indicating a lack of awareness of the issue. Others reported that in their service health assessments were based around questions about side effects of medication or other symptoms but did not cover health prevention initiatives such as cancer screening.

Triangulation of themes across the groups

Through triangulation of data from the three groups, it was possible to identify five overarching themes for which there was at least partial agreement. Overarching themes and constituent barriers and facilitators are summarised in Table 8.

Table 8. Overarching themes and constituent barriers and facilitators to cancer screening uptake.

Theme: Knowledge of screening programmes and processes	
Constituent barriers	**Constituent facilitators**
PLWDMI: Not knowing what to expect or what to do; Unsure of need for screening; Difficult to process information SP: Communication skills training not available to all MHP: Lack of knowledge of programme and/or procedures; Promotion of screening not prioritised; Lack of physical health expertise	PLWDMI: Wanting to be informed; Understanding the benefits of screening; Feeling health conscious; Encouragement MHP: Health promotion seen as their role; Aware that PLWDMI are at risk of cancer; Understanding emotional and practical barriers to screening uptake for PLWDMI
Theme: Knowledge of and attitudes regarding mental illness	
Constituent barriers	**Constituent facilitators**
PLWDMI: Lack of understanding of mental illness in screening professionals; Made to feel like a burden on health service; Stigma of mental illness SP: Lack of knowledge of severe mental illness; Find complex patients difficult MHP: Stigma of mental illness (among others)	PLWDMI: Staff being understanding; Staff knowledge of mental illness SP: Understanding of emotional and practical barriers to screening uptake for PLWDMI; Staff motivated to encourage screening for all groups; Importance of good communication skills recognised; Confidence to screen anyone associated with good communication skills
Theme: Health service delivery factors	
Constituent barriers	**Constituent facilitators**

PLWDMI: Screening environment aggravates mental health symptoms; Staff can be rushed; Staff can be rough; Exclusion from GP registers SP: Lack of time; No means of knowing patient needs in advance; Computer systems not linked MHP: Lack of a structured behaviour change approach; Lack of collaboration between healthcare services; No one has clear responsibility to promote screening; Patient's mental state; Lack of resources	PLWDMI: Continuity of care SP: Practice nurses can access patients' records; Reactive measures in place if notice given MHP: Diagnostic overshadowing known to be a problem; Willingness to promote screening; Cancer screening promotion included in routine health promotion
Theme: PLWDMI's beliefs and concerns	
Constituent barriers	**Constituent facilitators**
PLWDMI: Additional burden; Mental health symptoms reduce motivation for self care; Past negative experience; Embarrassment; Traumatising; Fear of bad news; Poor relationship with GP; Diagnostic overshadowing	PLWDMI: Feeling health conscious; Being anxious to avoid further health problems; Physical symptoms (e.g. finding a lump); Past positive experience; Good relationship with GP; Good relationship with Practice Nurse SP/MHP: Awareness of some of these difficulties
Theme: Practicalities for PLWDMI	
Constituent barriers	**Constituent facilitators**
PLWDMI: Appointment booking; Transport difficulties; Difficulty remembering appointments; Difficulty leaving the house due to mental health problems; Taking time off	PLWDMI: Familiar location; Reminders SP/MHP: Awareness of some of these difficulties

SP = screening professional, MHP = mental health professional

Discussion

In this study, PLWDMI and health professionals have identified service delivery and client related factors which hinder or support uptake of different types of cancer screening. We have reported in detail the barriers to and facilitators for cancer screening uptake by PLWDMI which were identified by three groups of stakeholders: PLWDMI, mental health professionals and healthcare professionals involved in delivering cancer screening. These factors were associated with five overarching themes: knowledge of screening programmes and processes, knowledge of and attitudes regarding mental illness, health service delivery factors, PLWDMI's beliefs and concerns, practicalities for PLWDMI. Here we relate our findings to existing research and discuss the implications of them for practice and policy changes which would improve equality of access to cancer screening uptake by PLWDMI.

Comparison with existing literature

Some of the identified barriers in this study, such as lack of knowledge of screening is a barrier found in other papers looking at other populations and those of the FOBT in the general population [14, 16, 18, 32-38]. Accordingly, it has been regularly identified that knowledge could also be a facilitator where participants wanted to be informed about screening, knew the benefits and received encouragement [14, 16, 18, 32-38]. Access difficulties have been found in studies of cancer screening in young women and BME groups [19, 33, 37], practical challenges around the FOBT have also been found in the general population [34]. We also found that some PLWDMI can struggle to process information in association with their mental health diagnosis.

Relationships with HCPs in general, are commonly identified as a barrier to accessing preventative healthcare in other studies of PLWDMI and BME groups [14, 18, 35-38]. Unique to our study was the identification of poor relationships between PLWDMI and cancer screening staff. We identified that some PLWDMI feel discriminated against due to their mental illness and/ or feel that their physical health needs have been overlooked due to HCPs focusing on their mental illness, as in previous studies [14, 18, 35, 36, 38]. In another study some participants had felt discriminated against due to their BME status [37]. In our study some screening professionals also demonstrated less than positive attitudes to working with PLWDMI. In our study positive interactions or good relationships with screening staff were identified to be a facilitator of screening in support of other studies of PLWDMI [14, 16, 18, 35, 36]

Anticipation of negative experiences was also identified in oral healthcare in PLWDMI and cancer screening this may be associated with the discomfort which can be involved with screening procedures [14, 16, 18, 32-34, 36, 37]. The experience of screening as traumatising and staff as rough was highlighted in one study of oral healthcare in PLWDMI [36]. Anticipation of a positive screening experience was a facilitator of cancer screening in studies of PLWDMI and young women [14, 33].

Our study identified that it can be difficult to leave the house due to mental health symptoms, this was supported by findings of one previous study in PLWDMI [18]. The finding that services fail to accommodate mental health needs is specific to PLWDMI [14, 36, 38], the importance of accommodation of other group's specific needs was identified in studies of cancer screening in BME groups and young women [33, 37]. In addition, some of our participants reported that they had been excluded from healthcare settings due to mental health problems. Our work also confirms findings from the USA [18, 39], showing that the way services are organised, particularly where there is a lack of integrated care, can impact on cancer screening uptake in PLWDMI.

Our in depth interviews found that some mental health professionals were willing to promote cancer screening, but that others did not see this as part of their role. This supports findings from a survey of mental health professionals in one NHS Mental Health Trust that although mental health professionals expressed positive attitudes towards physical health promotion in general, attitudes to cancer screening promotion were ambivalent [40].

Strengths and limitations of the study

We have undertaken a qualitative interview study of 85 individuals (PLWDMI, screening professionals and mental health professionals). To our knowledge it is the first qualitative study in the UK study to investigate uptake of cancer screening in PLWDMI. Furthermore it appears to be the only qualitative study worldwide to have investigated all three types of cancer screening offered in the UK (cervical, breast and bowel).

We employed rigorous methods to ensure the validity of our findings. For instance we made coding checks - a sample of 30% of transcripts was independently assessed by another researcher to ensure agreement about the categories and whether selected data were representative of these. A multidisciplinary team of professionals (with experience of nursing, psychology, psychiatry and health services research) and service users were involved in all stages of the study including developing the interview schedules, verifying the initial coding framework and in the development and finalisation of the themes. We actively sought evidence of discordant data.

We recruited a large number of participants with a wide range of characteristics. Our recruitment strategy ensured, among PLWDMI, that people with a wide variety of diagnoses, illness impact and service use were represented. PLWDMI of different ethnicities and living in inner city, suburban and rural locations were included. The views of people who were regular attenders at cancer screening, had never attended and who had intermittently attended were sought. Similarly, the professionals we recruited represented a range of professions, worked in a wide variety of settings and varied widely in their level of experience. Although the barriers and facilitators to cancer screening uptake that we have identified do not appear to be linked to participant characteristics, we can be confident that we have captured views from people with a wide range of views, concerns and experiences.

A further strength of the study is that we have been able to combine the perspectives of three key stakeholder groups: PLWDMI, screening professionals and mental health professionals. This enables us to identify where views and experiences are at odds between groups and where they concur. For instance, many PLWDMI would like more time with health professionals, but health professionals report lack of time. Within all three groups, the majority felt cancer screening was important, but among some professionals there was evidence of disagreement as to who is responsible for promoting it in PLWDMI.

The views that we have elicited provide rich data on processes relating to being invited to screening, attending and taking part in screening procedures. The receipt of results was not discussed, though it is likely that some of our identified barriers will relate to this too, for instance difficulties in receiving post when admitted to hospital for long periods.

Our data covers all three cancers addressed in the current UK National Cancer Screening programme. A limitation was that few males were recruited. This was partly due to the general, well recognised difficulty recruiting males to research studies ([41]), but also because the male sample was restricted to a narrow and older age range so the sampling frame for this group was small. For similar reasons, fewer of our participants were at the younger and older ends of the age spectrum in PLWDMI. In London, we were able to recruit breast cancer screening staff as the hospital in which this take place is within King's Health Partners (the Academic Health Science Centre in which the London team are based). In Dorset breast cancer screening facilities are not linked to the Trust from which participants were recruited, hence the views of screening staff in Dorset are not included here. We did, however, recruit via snowballing three professionals involved in screening working outside of London. Similarly, we recruited low numbers of medical practitioners (GPs, psychiatrists); though of the views of those we recruited appeared to concur with those of other professionals.

As with all studies where participants 'opt in', we acknowledge that both PLWDMI and staff who place importance on pro-health behaviours may have been more likely to have been recruited, as well as PLWDMI who have had particularly poor experiences, although diverse views were evident.

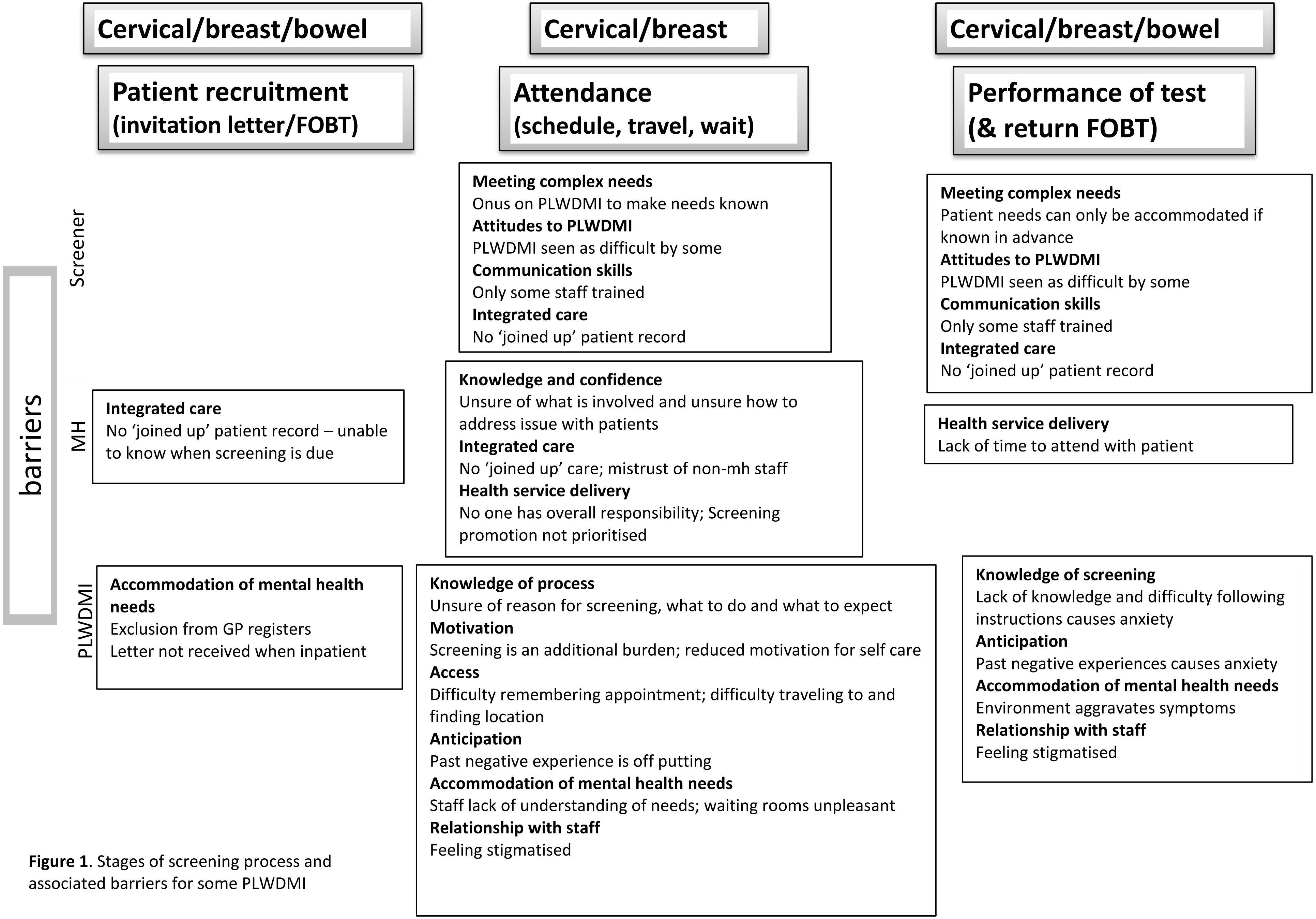
Implications for policy and practice

We consider here how the identified barriers impact upon the different stages of the cancer screening process. We then detail evidence based interventions for promoting cancer screening uptake in other populations and explore these in relation to our findings in order to determine which may be effective for PLWDMI. Finally, we identify other relevant interventions which our findings suggest may be of use in promoting cancer screening uptake in PLWDMI.

Stages of the cancer screening process

Examination of our data shows that the identified barriers and facilitators to screening uptake are relevant at different stages of the screening process. For instance, at the point of invitation to screening, or when sending out the FOBT for bowel cancer testing, PLWDMI will not receive post if they are admitted to hospital and will not be invited if they are not registered with a GP. Lack of integrated care means that mental health staff will not know if a PLWDMI is overdue for a test. At the point of attendance for screening and at the point of screening delivery, it is clear that important barriers and facilitators will vary between individuals.

To understand how best to intervene in order to facilitate uptake of cancer screening by PLWDMI, we have mapped the barriers identified by each participant group to the different steps within the screening process; this is depicted in Figure 1.



	Cervical/breast/bowel **Patient recruitment (invitation letter/FOBT)**	Cervical/breast **Attendance (schedule, travel, wait)**	Cervical/breast/bowel **Performance of test (& return FOBT)**
Screener		**Meeting complex needs** Onus on PLWDMI to make needs known **Attitudes to PLWDMI** PLWDMI seen as difficult by some **Communication skills** Only some staff trained **Integrated care** No 'joined up' patient record	**Meeting complex needs** Patient needs can only be accommodated if known in advance **Attitudes to PLWDMI** PLWDMI seen as difficult by some **Communication skills** Only some staff trained **Integrated care** No 'joined up' patient record
MH	**Integrated care** No 'joined up' patient record – unable to know when screening is due	**Knowledge and confidence** Unsure of what is involved and unsure how to address issue with patients **Integrated care** No 'joined up' care; mistrust of non-mh staff **Health service delivery** No one has overall responsibility; Screening promotion not prioritised	**Health service delivery** Lack of time to attend with patient
PLWDMI	**Accommodation of mental health needs** Exclusion from GP registers Letter not received when inpatient	**Knowledge of process** Unsure of reason for screening, what to do and what to expect **Motivation** Screening is an additional burden; reduced motivation for self care **Access** Difficulty remembering appointment; difficulty traveling to and finding location **Anticipation** Past negative experience is off putting **Accommodation of mental health needs** Staff lack of understanding of needs; waiting rooms unpleasant **Relationship with staff** Feeling stigmatised	**Knowledge of screening** Lack of knowledge and difficulty following instructions causes anxiety **Anticipation** Past negative experiences causes anxiety **Accommodation of mental health needs** Environment aggravates symptoms **Relationship with staff** Feeling stigmatised

Figure 1. Stages of screening process and associated barriers for some PLWDMI

Interventions to promote cancer screening uptake

A Cochrane review [28], conducted by two of the current authors (EB, PW) and others, found no trials of interventions to increase cancer screening uptake in PLWDMI. However, other systematic reviews [25-27] have demonstrated the effectiveness of a range of interventions to increase cancer screening uptake in the general population.

In Table 9, we have mapped our findings to the interventions identified by the most recent and comprehensive systematic review [26]. We conclude that most of these interventions would help some PLWDMI, but that others need more personalised or specialist help.

Table 9: Interventions to increase uptake of cancer screening in the general population: potential in PLWDMI

Interventions found effective in the general population from a review by Camilloni et al 2013 [26] (level of evidence if stated)	**PLWDMI – study theme** and explanation	**Likely to work in PLWDMI?**
Postal reminders (modest evidence)	**Access** – reminders were considered useful by some **Accommodation of mental health needs** – not received if patient currently an inpatient	May help those who have difficulty remembering appointments, but official letters are off putting to some. Inpatients will not receive reminders Text reminders may feel less threatening, though this needs to be tested.
Different styles of letter – short less detailed	**Knowledge** – some report difficulty processing information	May help as some wanted more and clearer information
GP signs invitation (modest, positive effect)	**Relationship with staff** – reports of poor relationships, especially in primary care; accommodation of needs – some excluded from GP registers	Will be ineffective in those who have a poor relationship with their GP; it would be difficult to know this in advance
Public information campaigns (heterogeneous results)	**Motivation** – some people had been inspired to attend due to public information campaigns	Some participants mentioned Jade Goody (who died of cervical cancer), but as stated in the review evidence for the effectiveness such campaigns is mixed and this is likely to be the case also for populations of PLWDMI.
Scheduled *versus* open appointment (positive effect)	**Access** – some people experience difficulty remembering appointments; **Anticipation** –	Some people need help to attend; scheduled appointments (which can

	past negative experience may put people off attending	be changed according to need) may help but the option of open appointments would help those with fluctuating symptoms (e.g they may be more likely to attend when feeling well)
Reduce logistic barriers (very effective)	**Access** – longer opening hours, help travelling to and finding location may help	Yes, especially as barriers were multiple and individualistic
Self sampling device to non-responders increases cervical cancer screening in non-responders	**Accommodation of mental health needs** – kits mailed to patient home, may not be received if the patient has been admitted. **Anticipation** – fear of doing it wrongly, traumatising	Evidence around FOBT suggests that some would like this, but others would need help to conduct the test. May be helpful for women who find cervical screening traumatising.
Mailing FOBT kit better than inviting to pick up	n/a – kits are mailed – **Accommodation of mental health needs** – kits mailed to patient home, may not be received if the patient has been admitted.	Kits are already mailed; this test could be done whilst the PLWDMI is in hospital if kits were available there.

Other potential approaches to promoting cancer screening uptake in PLWDMI

Through reflecting on the themes, barriers and facilitators found in our study, the study team have identified a number of potential changes in services or practice which could optimise access to and improve the experience of cancer screening for PLWDMI. These are summarised in Table 10 and discussed here.

It is clear from our findings that some screening professionals may benefit from mental health education. However, previous research [42] indicates that although non-mental health professionals may say they would like such training, they do not always prioritise it. Training may therefore need to be mandatory. Similarly, mental health professionals need to be better informed about cancer screening programmes.

A range of approaches to training is possible; this and previous work [42] suggests that mental health training should include consideration of clinicians' attitudes to working with people with mental health difficulties as these affect management decisions. Filmed social contact interventions have been found to reduce stigma around mental illness [43]; a narrative-based film informed by the findings of this study could be developed and tested for screening and mental health professionals. Such a film may also be helpful for health promotion within the population of PLWDMI which this study also shows is needed. Educational material informed by the target population is likely to be viewed as more credible than that produced by professionals [44].

This work, and work in the general population [26], highlights the individualised nature of barriers and facilitators to cancer screening uptake, so a tool or decision aid to identify and resolve barriers could be developed for use by PLWDMI in conjunction with professionals. Decision aids are designed to help people to weigh up the pros and cons of different choices and to help them to understand what is important to them. They therefore support shared decision making and self-management which are central to effective health care. Decision aids are an evidence based approach to facilitating behaviour change and could replace the informal, conversation approach to health promotion described by some participants as currently in use and which is unlikely to be effective. A Cochrane review of decision aids for people facing health treatment or screening decisions [45] identified 115 RCTs (total N = 34,444) comparing decision aids with usual care or an alternative. The review found high-quality evidence that decision aids improve people's knowledge of options and reduce their decisional conflict.

Decisional conflict is important for uptake of cancer screening which must be based on informed consent. An Australian study of 879 women [46] found that providing Information on over detection of breast cancer within a decision aid increased the number of women making an informed choice about breast screening. Informed consent and decisional conflict was not discussed by our participants, but a decision aid for PLWDMI to help decisions around disclosure of mental health status in employment situations was found to be feasible and to reduce decisional conflict [47].

The Equality Act 2010 [48] places a legal responsibility on health services to make reasonable adjustments to ensure people with SMI are not disadvantaged compared to the general population in accessing health care. Provision of reasonable adjustments in screening practice to meet mental health-related needs was discussed. Most of those in place are reactive, that is adjustments to services can be made if the patient asks for them in advance. Screening invitation letters do not currently routinely invite people to advise clinics of any special needs in relation to mental health, or give examples of the adjustments which PLWDMI may find helpful such as longer appointments or pre-appointment discussion of needs, therefore PLWDMI may not be aware that they can request such adjustments, or may not feel entitled to do so. Furthermore letters sometimes give a phone number for queries. This could be made easier for PLWDMI by extending the mode of contact to include texting, email and post as some PLWDMI find telephoning difficult.

Reactive accommodation places the onus on the service user to make a request which may be difficult for some. Special clinics for PLWDMI may help. In the UK, special care clinics for people with physical and mental health disabilities, learning disability, dementia and severe anxiety have been developed in dentistry [49]. In Australia, it was found [16] that women’s health clinics could be offered efficiently in conjunction with hospital based psychiatric services and that they were helpful and the report by Black Cancer Care [19] noted that one London breast screening service already runs a dedicated clinic for women with special needs including mental illness, though this was not evaluated. Our findings suggest that some PLWDMI would value a special cancer screening clinic.

Our work and that of others [50] highlights strongly the need for more integrated care and support for PLWDMI to access physical health care including cancer screening. We make some specific suggestions around cancer screening in Table 10, but a large body of evidence exists in regard to how to integrate better mental and physical health services. For instance a comprehensive review [50] recommends use of information sharing systems, shared protocols, joint funding and commissioning, co-located services, multidisciplinary teams, liaison services, research, navigators and reduction of stigma.

Finally, outreach based interventions may be effective in overcoming motivational barriers to taking up cancer screening. For instance, the Black Cancer Care report [19] noted that a health navigator outreach service for Black women was effective and advocated this for PLWDMI. A navigator is a single named individual who can help a PLWDMI to navigate their way through health (or other) systems. The Mental Health Foundation report into integrated care [50] argues that piloting and evaluation of such a role should be a research priority.

Our work suggests a large number of possible approaches to improving cancer screening uptake in PLWDMI. This is because our findings indicate that barriers and facilitators operate at service, practitioner and service user levels; and that PLWMI are not a homogenous group in their needs and preferences regarding cancer screening.

It is also clear that there is no one service location for any intervention that will meet the screening needs of all PLWDMI. For example, many people with mental health problems are cared for solely in primary care, therefore citing an intervention in secondary mental health services will exclude this group, many of whom have significant and enduring mental health issues. For example 12/15 of the PLWDMI in our sample currently receiving care exclusively from primary care had been in secondary mental health services previously or were currently attending mental health day centres. If a primary care intervention is directed only at those on the Severe and Enduring Mental Illness registers held in primary care, as this register is restricted to those with diagnoses of schizophrenia, schizoaffective disorder and bipolar disorder, it will miss those with other diagnoses (20/45, 44% of those in the present study) who, as our study has found, can also experience important difficulties accessing and receiving cancer screening. If an intervention is based around the Annual Physical Health Check undertaken in primary care, this is only offered to those on the Severe and Enduring Mental Illness register and hence restricted to a small number of mental illness diagnoses. Furthermore, it has been reported that only 30% of eligible service users have the Annual Physical Health check [20]. There are potential benefits to locating interventions in the third sector [19] however not all PLWDMI access such organisations.

Implications for research

We have made recommendations for further research throughout this document, here we summarise the main issues. Rates of cancer screening uptake by PLWDMI in the UK are unknown and current systems do not allow us to determine this. In order to establish the true size of the problem, methods of gathering accurate data to determine rates of cancer screening uptake by PLWDMI should be developed and tested, this will not be possible without greater integration of mental health and screening services.

Whatever the extent of the problem, this study has identified barriers and facilitators to cancer screening uptake in PLWDMI, some of which are shared with other disadvantaged groups. Interventions, informed by our findings should be developed and tested. These should focus on ensuring that screening professionals understand the needs of PLWDMI in relation to cancer screening and are facilitated to address them; improving mental health professionals' knowledge of and ability to promote cancer screening; individualised help for PLWDMI to identify and overcome personally relevant barriers to cancer screening uptake and to make informed choices. Research into outreach and other interventions highlighted here and by others (e.g. Mental Health Foundation 2013) to improve integration of mental and physical health services should be prioritised.

Finally, future work should be conducted to understand issues for PLWDMI in relation to receiving results of cancer screening and their decision-making around this and receipt of future care especially should results be positive.

Table 10. Potential interventions for implementation or further research based on the qualitative research findings

Intervention type	**Potential intervention formats**	**Potential content**
Meeting the learning needs of screening professionals	• Lectures, locally and nationally via recording of lectures • Narrative-based film based on qualitative findings • Online learning module	Knowledge & understanding mental illness; how to work with complex patients; communication training; diagnostic overshadowing; anti-stigma; effect of screening environment on MH symptoms, trauma-informed care; range of possible accommodations & equality law supporting them; how to identify & resolve barriers to screening
Meeting the learning needs of mental health professionals	• Lectures, locally and nationally via recording of lectures • Narrative-based film based on qualitative findings • Online learning module	Screening programme & procedures; knowledge & confidence to promote screening; role of MH profs re physical health; SU vs prof responsibility for health; range of possible accommodations & equality law supporting them; how to identify & resolve barriers to screening
Meeting the learning needs of PLWDMI	• Modules in Recovery College syllabuses • Narrative-based film based on qualitative findings • Online learning and information resources	Screening programme and procedures; information about equality law and provision of reasonable adjustments in healthcare; strategies for requesting accommodations; how to identify & resolve barriers to screening and to identify facilitators; coping strategies regarding screening procedures
Barriers identification and resolution tool for use with PLWDMI	• Paper, embedded in clinical system or online tool • Use with support person (PC prof, screening prof, MH prof, peer supporter) • In conjunction with GP annual health check, add to MH physical check)	To include within it a decision aid for use if barrier is uncertainty re having test, and motivational interviewing prompts if applicable. To cover practical, social and psychological barriers. Could also include section on facilitators (e.g. support person, personal strengths)
Provision of accommodations in screening	• Add to invite letters with explicit invite to people with MH-related needs regarding screening to phone/email/text them	Longer appointments, specially trained staff, staff with excellent communication skills, non-stigmatising staff, trauma-informed care, pleasant waiting & clinic rooms, pre-screening discussion (phone or

practice to meet mental health-related needs	- Reasonable adjustments in cancer screening care plan (e.g. leaflet with checklist of potential options completed by SU or SU & HP) - 'Mental health-friendly' screening clinics as set-aside sessions in breast screening clinics and well woman clinics	visit), help to use anxiety reduction strategies
Integrated care and support	- Nurse-to-nurse (MHN & PN) intervention to arrange support for all non-attending PLWDMI who have not explicitly opted out - Women's health drop-ins in mental health services staffed by practice / sexual health nurse to include cervical screening & support re accessing breast screening as well as other aspects - Nurses dually trained as mental health and physical health nurses - Physical health teams in mental health care ensuring all checks have been met - Mental health nurses liaising with primary care clinics	These individuals work together with PLWDMI e.g. around barriers and accommodations etc. to optimise appropriate cancer screening and experience
Outreach	- Outreach provided by health navigators, practice nurses, mental health nurses, or peer supporters for non / delayed-attending PLWDMI	Proactive contacting of PLWDMI who have not had or are late having cancer screening to work together with PLWDMI e.g. around barriers and accommodations etc. to optimise appropriate cancer screening and experience. Repeated contact if person is too unwell at time of initial contact.

Conclusions

PLWDMI experience a range of barriers to receipt of cancer screening. Currently there is no systematic approach to promoting cancer screening uptake in PLWDMI. Evidence based approaches are needed to address inequity in service receipt, but this study suggests that interventions found to improve cancer screening uptake in the general population may not be sufficient. A range of interventions appropriate to different stages of the screening process have been proposed. Interventions at the personal, service delivery and policy level which take into account the barriers and facilitators of cancer screening uptake identified by this research should be developed and tested. Most importantly, primary and secondary care staff and policy-makers should work together to develop an integrated approach to cancer screening in this population and thereby reduce inequalities of care.

Research Team

Dr Elizabeth Barley is a Senior Lecturer at the Florence Nightingale School of Nursing and Midwifery, King's College London (KCL). She is a Chartered Health Psychologist and Registered Nurse with expertise in qualitative and quantitative research methods; her research interests are around the mental - physical health interface. She has published two recent systematic reviews concerning cancer and cancer screening uptake in people with severe mental illness.

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Professor Jackie Sturt is a Registered Nurse and Professor of Behavioural Medicine in Nursing at Florence Nightingale School of Nursing and Midwifery, KCL. She has expertise in qualitative methods and was joint PI on the recent NIHR funded 'Flurrie Study' which examined factors leading to low uptake of diabetic retinopathy screening in Primary Care.

Dr Sarah Clement worked at the Institute of Psychiatry, Psychology and Neuroscience as a Senior Research Fellow and Lecturer in Health Services Research, KCL. She now holds an honorary position there and is a Freelance Researcher. Her work includes studies on health care seeking and on women's experiences of medical procedures, and her current interests centre on trauma-informed healthcare. She has lived experience relevant to the present study.

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Collaborators and Acknowledgements

Ms Lana Samuels is a service user member of the project review group. She has provided advice on the rationale, methods, materials and dissemination of findings. She has also helped recruit PLWDMI to the study.

Ms Mariam Aligawesa MSC RMN, is a Psychiatric Liaison Nurse with South London and Maudsley NHS Foundation Trust. She has provided expertise during project review meetings and is working on a review of literature related to this work.

Ms Caroline Coleman (research nurse) and **Ms Rebecca Weekes** (research assistant) are recruiting participants in Dorset and conducting interviews with them.

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Appendix 1a: Interview Schedule for PLWDMI

Introduction

Thank you again for agreeing to take part in our study. We are looking at people's views about bowel/smear/mammogram cancer screening (select as appropriate based on age and sex as discussed when confirming demographic information). We are interested in your views whether or not you have taken part in screening in the past. So in your case, my questions will be about mammogram/smear/bowel (as appropriate). I'm sorry if some of the questions sound a bit similar (omit if just one screening type applies).

I'm just going to begin recording our conversation now... (or not if participant is not happy for this)

Where more than one screening programme applies: which type of screening would you like to discuss?

Knowledge

- Can you tell me what you know about screening for mammogram/smear/bowel cancer? (prompts: why it is done, who is eligible, how often you are invited, who conducts the screening and what happens during screening)?

- Have you ever been invited to take part in (mammogram/smear/bowel) cancer screening? Can you tell me a little about that (when, how often)?

- For people who have experienced screening (and for each type of screening for which the participant is eligible): What was it like going for mammogram/smear screening (or doing the bowel cancer screening test)?

- What did you expect to happen when you went for screening?

- What was it like waiting for the results of your screen? (prompts: were you thinking about it much, did you feel anxious, did anyone help you to interpret the results, good/bad results?)

- For people who have not experienced screening (for each type of screening for which the participant is eligible):
- Can you say something about why you didn't take up the offer of mammogram/smear/bowel screening? (choice, emotions, practicalities)?

- If you did go for screening, what would you expect to happen? Do you know what happens when people go for smear/mammogram cancer screening/do the bowel cancer screening test?

Skills

- Did/do you know what to do in order to obtain (bowel/smear/mammogram) screening if you wanted it? (prompts: who to ask, where to go, how to get there, what to do?)
- How able do/did you feel to make requests to suit your needs (e.g. for a longer appointment time, or to see a health professional of a particular gender)?
- How easy would it be for you to carry out the bowel cancer screening test (what help would you need, what is difficult, what would make it easier)?

Social/professional role & identity

- How did/do any beliefs or values about the way you live your life influence your decision whether or not to take up mammogram/smear/bowel screening? (e.g. cultural, religious, spiritual, family values)

Beliefs about capabilities

- How confident were you about going for mammogram/smear screening (and/or carrying out the bowel cancer test (collecting the samples for bowel cancer screening and sending them off)? (Did/(does lack of confidence affect whether or not you take part in screening?)
- What problems, if any, have you experienced going for screening?
- How did you overcome any problems (if at all)?
- How confident are you that you can take part in screening without feeling distressed before or during screening, or afterwards?
- Is there anything that would have made it easier for you?

Beliefs about consequences (anticipated outcomes)

- What do you think are the benefits to you of having cancer screening (if any)? (prompts: finding things earlier and getting them treated, reassurance that all is well)

- What do you think are the disadvantages to you of cancer screening (if any)? (prompts: that it might be a distressing procedure, involve unempathic health professional(s), fear that it could lead to relapse or exacerbation of mental health problems, beliefs about false positives and negatives, about further investigations that might be indicated, beliefs about cancer treatment, morbidity and mortality)

Emotion

- Did or do any emotional factors prevent you from taking part in screening, or make it harder for you? (prompts: such as feeling very anxious or depressed, not valuing yourself very much, or feeling embarrassed about your body, health worries, fears about the procedures involved, or being diagnosed with cancer)?

Motivation

- How important would you say cancer screening is to you?
- Are there other concerns that are more important? (e.g. balancing mental health needs – which is the most important, does it vary over time?)

Memory, attention & decision processes

- How do/did you make the decision to take part in mammogram/smear/bowel screening?
- Did or do you have any problem remembering to go for the screening appointment/collect the samples for bowel screening or posting them off?
- What did you think of the information that came with the invitation for screening? (e.g. Did you find the information easy to understand? Was anything unclear? How could they make things clearer?
- How much do you think that problems with your mental health influence whether or not you go for mammogram/smear/bowel screening? (e.g. in terms of deciding to go or remembering to go or take part)

Social influences (norms)

- Does/did anyone influence your decision to take part in screening? (who, how?)

- What do/did people close to you (partner, relatives, friends) think about you getting screened for mammogram/smear/bowel cancer? How important is/was it to take their views into account?

- How supportive are they – do they remind you/encourage you? (partner/relatives/friend) E.g. helping to understand the pros and cons, making phone calls to confirm or change appointments, reminding you to go, going with you and waiting in the waiting room, or being with you when you had the test?

- Do you think you have been influenced to go for screening by any media reporting eg on TV news or programmes? Or by any community events (groups they attend, local health promotion ads or literature)? Or by mental health or cancer charities or user-led organisations? Or by health professionals not directly doing the screening (e.g. care coordinator, psychiatrist, GP)?

Environmental context & resources

- How did you get to the screening appointment (for mammogram, smear only)? How would you get there (if not previously attended or if not intending to go)?

- How convenient is this? (e.g. transport difficulties; appointment times; how it fits in with work/ family; health/mobility problems)

- Are there any problems with the bowel screening procedure in terms of how and where this can be done?

- Do money issues make a difference to whether or not you take up screening?

- What about finding the time to fit it in...?

- Was there any time when you were invited but felt too ill to attend, or were in hospital for e.g. or felt too ill to make a decision about whether to have the screening or to be able to have/do the procedures?

- OTHER ACCESS FACTORS – e.g. does their address change frequently (might they have missed a postal invitation)?

Behavioural regulation

- Are there things you need to do in order to prepare to go for screening (e.g. to arrange to help them have their screening related needs met – longer appointments, choice of professional, use of medication to help you feel less anxious during screening, having Cognitive Behaviour Therapy or learning other coping or relaxation techniques to help with medical procedures, having discussions with screening staff in advance of your appointment)?
- What part have health professionals played in influencing whether or not you have screening? Have you had any discussion about it with e.g. GP, psychiatrist, nurse, therapist, care coordinator? What did you talk about? Was it helpful? Did they do anything? Is there anything you would have liked them to do?

Finally...

- Is there anything else you would like to say about what health professionals and health services might do to what might make it easier for people with mental health problems to decide whether or not to go for cancer screening?
- And what could be done to make the experience of cancer screening better for people with mental health problems?

Appendix 1b: Interview Schedule for Mental Health Professionals

Introduction

Thank you for agreeing to take part in our study. We are interested in exploring health professional views of cancer screening in people living with mental illness. By mental illness we mean people who have mental health problems which last for a year or more and have a serious impact on people's lives. People living with mental illness may have diagnoses of schizophrenia, bipolar disorder, major depression, personality disorder or some anxiety disorders. We are looking at bowel, cervical and breast cancer screening for people living with mental illness.

I just want to ask you a few questions about your thoughts – please feel free to answer as honestly as possible. All information will be kept completely confidential. Are there any questions you would like to ask me before we start? (Turn on recorder)

Knowledge

- Can I start by asking what you know about the National Cancer Screening Programmes e.g. cancer types, who are eligible, frequency of screening?
- How do you see your role in terms of promoting cancer screening?
- What do you know about the link between severe mental illness and cancer survival?
- What factors do you think might contribute to fewer people living with mental illness getting screened for cervical and breast cancer? What about bowel cancer?

Skills

- Thinking about health promotion generally, what skills do you feel you have in this field?
- How easy is it to access the necessary information to help your patients with mental illness attend for screening (e.g. where, when, adjustments)?

Social/professional role & identity

- How far do you consider that it is part of your professional role to promote cancer screening in people with mental illness?

Beliefs about capabilities

- How easy is it to promote cancer screening to people with severe mental illness?
- How confident are you of overcoming any difficulties doing this if/when you encounter them?

- Would you say you experience any specific problems due to lack of confidence in this area?
- Is there anything that would make it easier for you?

Beliefs about consequences (anticipated outcomes)

- What do you think are the costs and benefits of promoting cancer screening in this group? For example, what will happen if you do promote screening? Might there be disadvantages - heavier workload, dealing with anxiety/distress, causing relapse or exacerbation of existing mental illness?
- How do you feel if you omit to promote screening when you could?
- What do you think are the pros and cons for people living with mental illness regarding cancer screening?

Motivation

- How important would you say the promotion of cancer screening in this group is to you?
- Are there any financial or other incentives for you to engage people living with mental illness in cancer screening?
- Are there other concerns that take priority/are more important?
- Are there times when mental health needs outweigh cancer screening needs *(When? In which situations?)*

Memory, attention & decision processes

- How do you make the decision to promote screening or not? Is this something you usually do?
- How do you remember to promote cancer screening?
- How much of a priority is it (screening people living with mental illness)? Are there any protocols for care of this group of people?

Environmental context & resources

- Is there a system for promoting screening in your practice/workplace? For example is there someone who has overall responsibility? Are there computer prompts? Are there any physical health questionnaires you use with people living with mental illness which include cancer screening?

- Is there an impact on workload? In terms of staff resources, being able to offer sufficient time?

- Is there a system for re-inviting people who DNA?

- What happens for other groups, e.g. those with learning disabilities, physical disabilities?

- Could the procedure for these groups be applied to people living with mental illness?

Social influences (norms)

- Is there anyone at work who influences your decision to promote screening or not e.g. colleagues/managers? (who, how?)

- What is the general culture at work in relation to promoting cancer screening in this group?

Behavioural regulation

- Is there extra work or planning involved in organising screening for people living with mental illness? (longer appointments, choice of professional, use of medication, CBT, pre-visit discussions).

Emotion

- Do any emotional factors affect whether or not you promote or conduct cancer screening with people in this group? *(prompts: anxiety, concern, stress, burnout).*

- Finally, is there anything you would like to add to what we've discussed about cancer screening in people living with mental illness?

Appendix 1c: Interview Schedule for Screening Professionals

Introduction

Thank you for agreeing to take part in our study. We are interested in exploring health professional views of cancer screening in people living with mental illness. By severe mental illness we mean people who have mental health problems which last for a year or more and have a serious impact on people's lives. People living with mental illness may have diagnoses of schizophrenia, bipolar disorder, major depression personality disorder or some anxiety disorders. We are looking at bowel, cervical and breast cancer screening for people living with mental illness.

I just want to ask you a few questions about your thoughts – please feel free to answer as honestly as possible. All information will be kept completely confidential. Are there any questions you would like to ask me before we start? (Turn on recorder)

Knowledge

- What is your experience of screening people living with mental illness?
- How do you think having a mental illness might affect the needs of this group when they undergo screening?
- What adjustments can you make to your practice to accommodate people living with mental illness? (is this a knowledge question?)
- What do you know about the link between severe mental illness and cancer survival?
- What factors do you think might contribute to fewer people living with mental illness getting screened for cervical and breast cancer? What about bowel cancer?

Skills

- Do you feel you have the necessary skills when it comes to screening people living with mental illness?
- What additional training, if any, do you think would be useful?

Social/professional role & identity

- Is it part of your professional role to promote cancer screening in people living with mental illness?

Beliefs about capabilities

- How do you promote screening in people living with mental illness? How easy is it to promote cancer screening in this group?

- How confident are you of overcoming any difficulties conducting screening in people living with mental illness?

- Would you say you experience any specific problems due to lack of confidence in this area?

- Is there anything that would make it easier for you?

Beliefs about consequences (anticipated outcomes)

- For those involved in promoting screening: What do you think are the costs and benefits of promoting cancer screening in this group? For example, what will happen if you do promote screening? Might there be disadvantages - heavier workload, dealing with anxiety/distress, causing relapse or exacerbation of existing mental illness?

- How do you feel if you omit to provide screening when you could?

- What are the pros and cons for people living with mental illness regarding cancer screening?

Motivation

- How important would you say cancer screening in this group is to you?

- Are there any financial or other incentives for you to engage people living with mental illness in cancer screening?

- Are there other concerns that take priority/are more important?

- Are there times when mental health needs outweigh cancer screening needs? *(When? In what situations?)*

Memory, attention & decision processes (For those involved in promoting screening)

- How do you make the decision to promote screening or not? Is this something you usually do?

- How do you remember to promote cancer screening?

- How much of a priority is it (screening people living with mental illness)? Are there any protocols for care of this group of people?

Environmental context & resources

- How does your system of screening work? *E.g do you provide opportunistic screening? Annual checks? Do you use computer prompts and reminders?*

- For people in breast cancer screening units/sexual health clinics: Do you know in advance if someone coming for screening may have mental health problems? If so, how do you prepare for this (if at all)?

- Is there an impact on workload? In terms of staff resources, being able to offer sufficient time?

- Is there a system for re-inviting people who DNA?

- What happens for other groups, e.g. those with learning disabilities, physical disabilities?

- Could the procedure for these groups be applied to people living with mental illness?

Social influences (norms)

- Is there anyone at work who influences your decision to screen or not e.g. colleagues/managers? (who, how?)

- What is the general culture at work in relation to screening for cancer in this group?

Behavioural regulation

- Are there any procedures to encourage screening in this group of people? E.g longer appointments, choice of professional, use of medication, CBT, pre-visit discussions)?

Emotion

- Do any emotional factors affect whether or not you conduct cancer screening with people in this group? *(prompts: anxiety, concern, stress, burnout).*

- Finally, is there anything you would like to add to what we've discussed about cancer screening in people living with mental illness