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Development and preliminary evaluation in community mental health teams of a cervical screening informed-choice tool for women with severe mental illness in England: a mixed-method study

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ABSTRACT

Objectives Women with severe mental illness (SMI) face barriers to cervical cancer screening, leading to lower participation and poorer outcomes. This research aimed to develop and test an informed-choice tool to help women with SMI make informed decisions about screening attendance.

Design The tool was developed using a realist review of physical health interventions and a systematic review of informed-choice tools for people with SMI. A mixed-methods approach informed its development. Usability and acceptability were assessed through semistructured interviews and the think-aloud method with service users (n=18), clinicians (n=16) and key informants. A preliminary proof-of-concept (n=25) evaluated the impact on decisional conflict—the uncertainty around making value-sensitive choices.

Setting and participants Conducted in two National Health Service (NHS) Mental Health Trusts (urban and rural). Participants included women with SMI accessing secondary mental healthcare, clinicians and service user groups. A key informants' group guided clinical content.

Intervention A cervical screening informed-choice leaflet and an accompanying video.

Results The tool was usable and acceptable, especially for women overdue or never screened. It may reduce decisional conflict and increase screening uptake, potentially improving survival. An National Institute for Health and Care Research (NIHR)-funded feasibility trial (Improving uptake of cervical screening in people with severe mental illness (OPTMISE)) is underway. The current UK government guidance on *Support for people who find it hard to attend cervical screening due to having a mental health condition or having experienced trauma or abuse* is based on this research.

Conclusions Future research may involve further assessments of the real-world impact of the tool and its adaptation to other health-related decisions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Service users, service user groups, health professionals and a key informants' group were involved during the development and preliminary evaluation of a cervical screening decision-making tool.
⇒ The tool was theoretically underpinned and guided by two published systematic reviews conducted by the authors.
⇒ The acceptability and usability of the tool were tested by service users and health professionals in community mental health teams.
⇒ The tool was tested as a paper leaflet in a proof-of-concept study using validated scales.
⇒ Other formats of the tool may be more acceptable to some women with SMI.

BACKGROUND

Within the general population, people with severe mental illness (SMI) face one of the greatest health inequality gaps.[1] A reduced life expectancy of 10–20 years for individuals with SMI compared with the general population has been reported in the UK[2–4] and other high-income countries, such as the USA, the Nordic countries, Japan and Israel.[5–8] This life expectancy gap is even wider in low-income and middle-income countries.[9 10] It was reported that a significant cause of the mortality disparity is attributed to preventable and treatable long-term physical health conditions, with cardiovascular disease and cancer as the first and second leading causes of death, respectively.[11 12] While the epidemiological evidence regarding cancer incidence in people with SMI is inconclusive, excess cancer mortality in people with SMI has been reported consistently.[13–18] Results from UK

and international studies have found cancer mortality to be higher among people with SMI than in the general population.[19–24]

An important factor that contributes to poorer survival rates of people with SMI after a cancer diagnosis is unequal access to cancer screening.[19 25] Evidence on cancer screening uptake from the UK and internationally indicates that for a range of cancers, screening attendance is significantly lower in people living with SMI compared with the general population.[16 26–37] Among those who were registered with a General Practitioner (GP) in England in September 2018, people with SMI were 20% more likely not to have participated in cervical screening within the recommended time period than those without SMI. This evidence reflects inequality in the uptake of England's national cervical cancer screening programme.[38] A delayed cancer diagnosis, which may be due to postponement in help-seeking,[14] may not fully explain the mortality differential, but it is an important factor. Among women with SMI, delays in help-seeking are particularly problematic because women may be at an increased risk of invasive cervical cancer due to the prevalence of other risk factors for cervical cancer. These include a lifetime incidence of sexual abuse (69%), high rates of smoking and risky sexual behaviour associated with manic episodes.[11 32 39]

Deciding whether to attend a screening involves making an informed choice that includes consideration of the advantages and risks of the screening process.[40 41] Consideration of pros and cons may be part of most people's decision-making; however, people with SMI may face additional barriers (such as delusions and paranoia or denial of physical symptoms) that are specific to them and which may affect their decision-making[42] and thus cancer screening uptake.

For those with poor decision-making skills and/or unmanaged psychiatric symptoms or those who lack decision-making experience, making even a small choice can be empowering.[43–45] Research has shown better health outcomes for those with a mental health diagnosis as a result of active participation in decision-making.[46 47] However, people living with SMI commonly report poor continuity of care[48] and difficult relationships with health professionals, particularly in primary care,[42 49] so shared decision-making tools may not be appropriate for everyone within this population. In addition, primary care clinicians face time constraints in using a shared decision-making tool;[50] therefore, an informed-choice tool, which could be used independently or with a supporter of choice (eg, family member, friend or support worker), might be a more suitable format for assisting women with SMI in their decision to attend cancer screening. Informed-choice tools seek to support patient autonomy and ensure that individuals are neither deceived nor coerced[51] in making a decision.

This paper describes the development, acceptability, usability and preliminary evaluation of a cervical screening informed-choice tool (*hereafter* 'the tool') for women with SMI, which aims to improve the ability of this group to decide whether to attend cervical screening or not. It also provides information on what support is available and where to access it to improve the experience of cervical screening. The final version of the tool is an A5 colour leaflet (16 pages)[52] and is freely accessible online. It contains seven sections: '*What is cervical screening?*', '*Booking your appointment*', '*Before your appointment*', '*During your appointment*', '*After your appointment*', '*Looking after your health*' and '*Getting Support*'. It states: 'The leaflet can be read on its own or can be used as a decision-making tool to discuss whether to attend cervical screening with a friend, relative, partner, support worker or other clinician.' The leaflet can be brought to the appointment, as it contains a 'tick box' section, which lists specific things that women may want the practice nurse to be aware of, but that they don't wish to discuss. These include 'I found it hard to leave my house', 'I hear voices' and 'I have experienced trauma'. In addition, a 90 s animated video illustrating the key points of the tool, including how to use the tick box page as a 'disclosure tool', was developed during the study and is freely available.[53]

Among NHS cancer screening programmes, cervical screening was selected for this research, given that attendance rates for cervical screening in the UK have been suboptimal for the past two decades. The NHS England cervical screening programme annual report[54] found that 68.7% of women aged 25–64 years had attended screening within the recommended period, compared with 69.9% the previous year. There is a clear need for a tool to support this group's uptake of cervical screening.[55] However, we found no evidence in the existing literature of any individual-level intervention for women with SMI regarding cervical screening.[56] The primary aim was to develop and test a decision-making tool to surmount or reduce the impact of barriers to cervical screening in women with SMI.

METHOD

Design

The development of the tool was underpinned by the Medical Research Council's guidance for developing complex interventions.[57] This research consists of three stages: testing the usability of the tool, testing its acceptability and conducting a preliminary evaluation of its proof-of-concept. Prior to this research, two reviews were conducted: a realist review of physical health interventions for people with SMI and a systematic review of informed-choice tools for this population.[58 59] The first stage assessed the acceptability of the tool with women with SMI and other stakeholders. The second stage tested the tool's usability with women with SMI and health professionals using the think-aloud method.[60] This method has been used successfully to test smoking cessation interventions with participants with SMI.[15 61] Readability levels were assessed two times using V.0.3 and V.0.4

of the tool (which included changes from the usability testing phase).

The final stage was conducted as a preliminary evaluation of the tool's impact on cervical screening decision-making with women with SMI. Underpinned by the Theory of Planned Behaviour[62] and using a mixed-method design, the data from this final stage were used to interpret qualitative data on the acceptability and usability of the tool. The research received a favourable assessment from the university ethics committee on 7 December 2017 (Reference: UWL/REC/CNMH-00301) and the National Research Ethics Service (Ref: 18/SC/0123) on 16 April 2018.

Setting

The research settings were three community mental health teams (CMHTs): two within an inner-city London Trust, where the research team had established links, and one rural/coastal NHS Trust, which had been involved in prior research related to this study.[42]

Participant recruitment criteria

Eligible women (and trans men) were those who were (a) diagnosed with SMI, including schizophrenia, schizotypal and delusional disorders, bipolar affective disorder or severe depressive episodes with or without psychotic episodes;[63] (b) able to read English and (c) currently receiving adult (aged 18–65 years) outpatient mental health services in either NHS Trust. The upper age limit reflects the Cervical Screening Guidelines' recommended age group (24–65 years). Women with SMI were excluded if their clinical team considered them to lack the capacity to consent or to be currently too unwell to take part. Eligible health professionals included those who were (a) working in secondary mental healthcare (doctor, clinical psychologist, nurse, social worker or nurse working as a care coordinator) and (b) currently working for either NHS Trust.

Sampling and recruitment procedure

For the acceptability testing of the tool (Phase 1), sample sizes of n=10 for each type of participant (women and healthcare professionals) were based on the estimated number required for theoretical saturation informed by previous similar research.[64 65] For the usability testing of the tool (Phase 2), sample sizes of n=8 and n=6 for each type of participant (women and healthcare professionals) were based on the estimated number required for theoretical saturation.[60] To evaluate the proof-of-concept of the tool (Phase 3), a conservative sample size of n=25 for women was based on previous similar studies.[66–68]

Convenience sampling was used for women with SMI. For health professionals, convenience sampling plus snowball sampling was chosen as the sampling method.[69]

Patient and public involvement (PPI)

Patients and the public informed at every stage of the development of the tool: women with SMI and service user groups, health professionals, carers, public health policymakers and third-sector organisations, such as cancer and mental health charities.

A multidisciplinary expert group—hereafter 'the key informants' group'—was established at the beginning of the research to inform the development of the tool iteratively: service user groups (n=4); specialised cervical screening clinics (n=4); charities (n=2); national public health stakeholders (n=2) and NHS clinicians/clinical academics with an interest in the physical health of people living with SMI (n=5).

PPI comprised six rounds:

- Round 1 consisted of collecting feedback on the draft research protocol and research materials before submission to the NHS Research Ethics Committee.
- Round 2 consisted of collecting feedback from a service user and carer group on the barriers and enablers to cancer screening. The service user focus group included carers of people living with SMI. Their feedback was incorporated when developing the section of the tool related to bringing along a friend/relative to the appointment.
- Round 3 involved the key informants' group to inform the development of a version of the tool appropriate for acceptability testing, including ensuring the content was unambiguous, clinically accurate and conformed with NHS cervical screening guidelines.[70 71]
- Rounds 4 and 5 consisted of email feedback on the tool from the key informants' group members. This included suggestions on where and how to disseminate the tool.
- Round 6, the final round of stakeholder involvement, consisted of feedback on the final iteration of the tool from the key organisations involved in its development.

Development of the tool

The development of the tool was informed by two reviews: a realist review to evaluate the effectiveness of interventions developed to increase the uptake of or access to physical health screening in people diagnosed with an SMI[58] and a systematic review to identify the specific design(s) and theoretical framework(s) used to develop the tool for people diagnosed with SMI and determine their effectiveness.[59] The following steps were used to develop the intervention based on the synthesised evidence from the systematic review (n=10 studies): identify barriers to decision-making (Step 1); theoretically underpin the intervention (Step 2); involve service users in the development of the tool (Step 3); test usability of the intervention (Step 4) and assess readability levels (Step 5).

People living with SMI may periodically face chronic executive function issues, including drowsiness or cognitive blunting.[72 73] To ensure accessibility of the tool for this group, who may have lower-than-average reading levels, the readability of draft versions of the tool was assessed using the Flesch Reading Ease and Flesch-Kincaid Scales.[74 75] The tool was designed using the

Dyslexia Friendly Guide.[76] The guide recommends using a dyslexia-friendly font (Arial was selected), a white background and a font size of a minimum of 12 points (14 was selected based on feedback from one of the service user groups from the key informants' group).

Using the barriers and enablers to cancer screening uptake in people with SMI previously identified[42]—which were coded using the Theoretical Domains Framework[77 78]—ensured that the development of the tool's components was theoretically underpinned. These barriers and enablers were linked to behaviour change techniques,[79] coded by two authors (FRLG and CL) and verified by a third (EB). These component behaviour change techniques[79] were selected and/or refined to promote screening behaviour within the tool. Each tool section was developed to address the identified barriers and promote the specific enablers.[42]

The key informants' group, together with service user groups, provided iterative feedback on the tool. V.0.1 of the tool was emailed in July 2018 to health professionals, who are members of the key informants' group (excluding the service user groups to avoid providing them with potentially inaccurate information), to ensure the clinical content of the tool conformed with current NHS cervical screening guidelines. The content was reviewed by Jo's Cervical Cancer Trust and Public Health England, as well as NHS health professionals working with the population of interest and/or vulnerable groups where there may be overlap. These include a GP with expertise in SMI, as well as health professionals working in specialist cervical screening clinics for the following groups: women who have experienced sexual violence (feedback from n=1 clinician), women who have survived female genital mutilation/cutting (n=2), women who have SMI and/or a history of substance misuse (n=1) and women on a mental health inpatient ward (n=1). The tool was revised for acceptability and usability testing in clinics.

Phase 1 (acceptability testing)

Every participant who gave consent to take part in the research—women with SMI (Phases 1–3) and health professionals (Phases 1–2)—completed a demographic and clinical (or) professional questionnaire covering demographic characteristics, clinical information (mental health diagnoses, duration of illness(es), whether participants had been for one or more cervical screening appointment(s) in the past and, if so, when the most recent appointment took place) and professional characteristics (profession, length of time in current role, work setting and length of time qualified). To ensure diversity of feedback, different individuals participated in each phase of the tool's development. Though women with SMI may present with several diagnoses, each participant is only reported once in table 1 and table 3.

Semistructured interviews with women diagnosed with SMI (n=10) and their health professionals (n=10) were conducted to assess the tool's acceptability and relevance and ensure no information was excluded. Following this feedback, the tool was modified.

Table 1 Demographic characteristics of study participants (service users)

	Acceptability of the tool (n=10), Phase 1	Usability of the tool (n=8), Phase 2
Gender, n (%)		
Female	10 (100)	8 (100)
Other	0	0
Age, years: mean (SD)	42.0 (7.9)	47.0 (7.9)
Recruitment sites	3	2
Ethnicity (grouped), n (%)		
White	5 (50)	6 (75)
Black/black British	4 (40)	2 (25)
Asian/Asian British	1 (10)	0
Self-report diagnosis, n (%)		
Schizophrenia spectrum	4 (40)	4 (50)
Bipolar disorder	2 (20)	1 (12.5)
Psychotic depression	1 (10)	1 (12.5)
Personality disorders	3 (30)	1 (12.5)
Depression and complex PTSD	0	1 (12.5)
Had cervical screening, n (%)		
More than once	7 (70)	8 (100)
Once	1 (10)	0
Never	1 (10)	0
Not yet eligible (invitations to first screen are issued at age 24.5 years)	1 (10)	0
Last cervical screening, n (%)		
In the last 5 years	6 (60)	6 (75)
Over 5 years ago	2 (20)	2 (25)
Never	1 (10)	0
Not yet eligible	1 (10)	0

PTSD, post-traumatic stress disorder.

Phase 2 (usability testing)

A revised version of the tool was then presented to a second group (n=8) of women diagnosed with SMI and health professionals (n=6) to test its usability using the 'think-aloud' method.[60] Feedback received on the tool's content was transcribed, analysed and incorporated into the tool once the interviews were completed to create the final version of the tool. This final version was then sent to all stakeholders involved in developing the tool.

Phase 3 (proof-of-concept study)

Instruments

As recommended by the Ottawa decision support framework,[67] the validated Decisional Conflict Scale (DCS)

(Parts A and B, with subscales: feeling uncertain, feeling uninformed, feeling unclear about values and feeling unsupported)[80] and the Stage of Decision-Making Scale[81] were selected for Phase 3 (evaluation of the proof-of-concept) to assess decisional conflict and readiness to engage in decision-making, respectively. The 'low literacy' version of the DCS, recommended for individuals with limited reading or response skills, was selected to mitigate any cognitive impairment of participants. In terms of psychometric properties, the DCS has been used[82] and validated[83] with people diagnosed with schizophrenia. The scale had adequate internal consistency (Cronbach's alpha values ranging between 0.78 and 0.84) and significant discrimination (p≤0.37) between service users who expressed certainty and uncertainty regarding decisions to continue with psychiatric treatment.[80] For the Stage of Decision-Making Scale, the construct is associated with a decisional conflict measure in the hypothesised direction. Early stages are associated with higher decisional conflict and later stages with lower decisional conflict.[81]

Procedure for Phase 3

Each woman participant who took part in the proof-of-concept study filled out the demographic and clinical questionnaire, the DCS and the Stage of Decision Making Scale.[80 81] The participant then engaged with the tool, had the opportunity to ask for any clarifications and was then asked to complete the scales again.

Analysis

The demographic and health data were summarised using descriptive statistics. A content analysis of the transcripts was conducted.[84 85] Preintervention and postintervention data from the DCS and the Stage of Decision-Making Scale[80 81] were analysed using SPSS (v.26). A Wilcoxon signed-rank test was used to compare the women's decision-making regarding cervical screening before and after using the tool. The effect size (r) of the change was also calculated.[86] This was interpreted as follows: r can range from −1 to 1; the effect size is greater the closer it is to 1 (or −1); r=0: no relationship; r<0: a negative relationship and r>0: a positive relationship.

RESULTS

Summary of the results from the acceptability and usability testing of the tool (Phases 1 and 2)

Consent to take part in the research was received from 18 women with SMI and 16 health professionals, who were recruited from two NHS trusts to provide feedback during the development of the tool. The characteristics are presented in tables 1–3. A total of n=8 women refused to take part in the study. Five women gave a reason for declining to take part: history of trauma, which they did not want to discuss (n=2); bad cervical screening experience (n=1) and refusal to go for cervical screening (no reason given, n=2). In addition, a key informants' group checked the clinical aspects of the tool and provided dissemination guidance.

Table 2 Demographic characteristics of study participants (health professionals)

	Acceptability of the tool (n=10)	Usability of the tool (n=6)
Gender, n (%)		
Female	6 (60)	4 (66.67)
Male	4 (40)	2 (33.3)
Other	0	0
Age, years: mean (SD)	43.5 (9.1)	42.0 (4.4)
Recruitment sites	4	4
Ethnicity (grouped), n (%)		
White—all	9 (90)	5 (83.33)
Black/black British—all	0	0
Asian/Asian British—all	1 (10)	1 (16.7)
Work setting (grouped), n (%)		
CMHT	7 (70)	4 (66.67)
Primary care mental health service	0	1 (16.67)
Psychiatric hospital	1 (10)	0
Recovery team	1 (10)	1 (16.67)
Liaison psychiatry	1 (10)	0
Profession (grouped), n (%)		
Nurse	4 (40)	2 (33.3)
Care coordinator	2 (20)	1 (16.67)
GP	1 (10)	0
Psychiatrist	3 (30)	1 (16.67)
Clinical psychologist	0	2 (33.3)
Length of time in current role, years: median (IQR)	5.0 (9)	5.75 (1)
Length of time since initial qualification, years: median (IQR)	13.5 (12)	9.5 (6)

CMHT, community mental health team; GP, General Practitioner.

Acceptability testing of the tool (Phase 1)

One of the sections of the tool deemed most useful by service users and health professionals was the 'tick box' pages (pages 8–9),[52] which list things that service users may want the nurse to be aware of but do not wish to discuss (eg, 'I have experienced trauma' or 'Please warn me before you touch me'). Results of the content analysis show that some revisions to the tool were requested (n=8 changes requested from service users and n=35 from health professionals). These included changes to the terminology to make the tool more accessible to all. Overall feedback on the tool from service users and health professionals was positive (n=28 positive comments from 10 health professionals and n=54 from 10 service users):

> It would be good if [the tool] got sent out into the post, you know when you have the letter for the

Table 3 Demographic characteristics of study participants (service users) (n=25)

Gender, n (%)	
Female	25 (100)
Other	0
Age, years: mean (SD)	42.0 (11.3)
Ethnicity (grouped), n (%)	
White—all	14 (56)
Black/black British—all	6 (24)
Asian/Asian British—all	5 (20)
Other	1 (4)
Self-report diagnosis, n (%)	
Schizophrenia spectrum	6 (24)
Bipolar disorder	6 (24)
Psychotic depression	2 (8)
Depression	4 (16)
Personality disorders	4 (16)
Depression and PTSD	2 (8)
Depression and eating disorder	1 (4)
Had cervical screening, n (%)	
More than once	17 (68)
Once	2 (8)
Never	3 (12)
Not yet eligible	3 (12)

PTSD, post-traumatic stress disorder .

> reminder, so they [women] can have a look at the leaflet, so it prepares them, it would give them more faith to book this test (service user)
>
> In a clinic, asking open-ended questions can sometimes be overwhelming for the patient (e.g. are you anxious about anything?), having the 'tick box' page is helpful (psychiatric nurse)
>
> Very useful to have this leaflet to hand out and then to follow-up with at the next appointment (…) It gives people a tool if they need extra help, it's written in the leaflet what they can ask for (…) leaflet is great, it's one of those things like sexual dysfunction for men on antipsychotics, don't always think to check, so leaflet is useful' (psychiatric nurse).

Two main contentious issues were raised during the interviews. The first was the terminology around SMI.

> it would be helpful to avoid using purely medical language for mental distress' (service user)

The consensus across service users was that making a specific reference to SMI was unnecessary. Similarly, health professionals worried that an overemphasis on 'SMI' might deter women attending, who may either feel that the tool is irrelevant to them or that they are being stigmatised:

> One of the beauties of the leaflet is that it doesn't go out of the way to state mental health, it's a really useful leaflet for everybody actually (…) we need to be connecting with them as people (…) it would turn some people off if it became focused on SMI (…) as professionals we categorise them, but the person walking in the street isn't thinking 'I have SMI', so we need to give them information in a way that gives them better access to available screening (Psychiatrist).

The second contentious issue raised was whether the tool should focus on the benefits of cervical screening or the risks of non-attendance.

> There is too much mention of the word 'cancer', might worry someone who has paranoia or health anxiety and they might think 'I'd rather not know' (Mental health nurse)
>
> Don't be afraid to be explicit about the risks involved if they don't go, don't be scared to use the word 'cancer' (Mental health nurse)

Following feedback from participants, an effort was made to balance the risks of non-attendance with the benefits of screening throughout the tool. Cancer prevention was highlighted in the section 'What is cervical screening?' The health promotion message to emphasise the benefits of screening appears in different sections of the tool, for example, 'Going for cervical screening when invited is the best way to protect yourself against cervical cancer' (page 4, 'What is cervical screening?') and 'These symptoms don't mean you have cancer and are often caused by other things, but it's important to get them checked' (page 11, section 'Looking after your health').

Usability testing of the tool (Phase 2)

Overall, feedback on the design of the tool was also positive:

> I think the colours are really good, it's quite friendly and opening, and it is quite informative, and I don't think it makes it too scary, which is nice because obviously when you mention the word cancer or screening, it's like OMG [Oh My God], and then people don't want to go but not the way you've done it (…) it's normally one page, or a boring booklet in black and white (service user)
>
> Perhaps the leaflet is a little long, might be overwhelming for patients who are quite anxious, but having said that there are no sections I would remove and also you don't want to undersell the importance of the test (Doctor)

During the think-aloud sessions, service users raised three contentious issues: the tool's length, the front cover image and the order of certain sections.

> Concentration is an issue with this group of patients, could we cut it down a little? (Psychiatric nurse)

> You can put two people on it [front cover image], and it's like little [speech] bubbles, and they are having a conversation and it's like (…) 'no don't be embarrassed', like a supportive friend, so there's two women talking and one is whispering to the other, coz that's how it starts, it has to be someone really clued on that says 'come on I'll take you there' (service user)

The front cover image was revised based on the suggestions received from service users and the key informant group. An illustrator was commissioned to conceptualise the image, which illustrates three women of different ages and ethnicities conversing on a couch about going for cervical screening. At a clinic in a CMHT, the author (FRLG) asked service users (n=3) and health professionals (n=2) to give feedback on the image. The service users (n=3) requested a larger font size for the speech bubbles in the image. This change was incorporated.

User testing with service users enabled the tool to be revised. This included refining the language used to increase readability, such as providing a definition and diagram for the word 'cervix'.

Proof-of-concept (Phase 3)

25 out of 40 women approached by their clinician gave consent to take part. Of the 15 who refused, 9 gave a reason: history of trauma (n=2), bad cervical screening experience (n=3), refusal to go for screening (no reason given, n=3) and does not want to discuss cancer screening (n=1). The demographic and health data are shown in table 3 below.

Decisional conflict

Results from Part A of the DCS indicated that the direction of change is towards having screening, though the small sample size was not statistically powered to detect a difference. There was a statistically significant reduction in decisional conflict regarding which cervical screening option participants preferred after using the tool (Z=–2.42, p=0.016, r=–0.34) (see table 4).

Decisional conflict scores improved (reduced) for all subscales postuse of the tool. The global and individual subscale decisional conflict scores were all below 25; scores below 25 are associated with making decisions.[80] A statistically significant overall reduction in decisional conflict after using the tool (Z=–2.81, p=0.005, r=–0.39) was also indicated. The direction of change is improving for each of the decisional conflict subscales: feeling uncertain (Z=–1.34, p=0.18, r=–0.19), feeling uninformed (Z=–1.63, p=0.102, r=–0.23), feeling unclear about values (Z=–1.34, p=0.18, r=–0.19) and feeling unsupported (Z=–1.60, p=0.109, r=–0.23); however, these reductions are not statistically significant.

Decision-making

Results from the Stage of Decision-Making Scale (see table 5) indicated that some women had begun to think about their decision regarding screening attendance. The direction of change of participants' overall stage of decision-making on screening attendance after using the tool was just positive, though changes were not statistically significant (Z=–0.17, p=0.86, r=–0.03).

DISCUSSION

This research has highlighted the potential impact that various barriers to cervical screening can have on women's choice of whether to attend and how this tool can help. By examining the qualitative data, it was possible

Table 4 DCS (parts A and B)

Part A—difficulty in making this choice				
	Before using the tool		**After using the tool**	
Which cervical screening option do you prefer?	***n***	**%**	***n***	**%**
Option 1: I will attend my cervical screening appointment	14	56	21	84
Option 2: I will not attend my cervical screening appointment	5	20	3	12
Option 3: unsure	6	24	1	4

Part B—median preuse-and postuse scores of the tool			
Category	**Median (IQR) before using the tool**	**Median (IQR) after using the tool**	**Statistic***
Total DCS	39 (135)	11 (231)	Z=–2.81, p=0.005, r=–0.39
Uncertainty subscale	6 (34)	0 (50)	Z=–1.34, p=0.18, r=–0.19
Informed subscale	15 (30)	3 (68)	Z=–1.63, p=0.102, r=–0.23
Values clarity subscale	10 (28)	4 (46)	Z=–1.34, p=0.180, r=–0.19
Supported subscale	11 (46)	4 (67)	Z=–1.60, p=0.109, r=–0.23

*Wilcoxon signed-rank test.
DCS, Decisional Conflict Scale.

Table 5 Stage of Decision-Making Scale (n=25)

How far along are you with your (cervical screening) decision?	Preintervention		Postintervention	
	n	%	*n*	%
I have not yet thought about the options	2	8	0	0
I am considering the options	1	4	**4**	16
I am close to choosing one option	1	4	1	4
I have already made a choice	21	84	20	80

to determine that the tool may improve the cervical screening experience of some women who either have already attended or are unsure about attending. It is also evident that some women with SMI may be at increased risk of having a negative screening experience compared with women in the general population. Research has shown that such a screening experience may reduce a woman's inclination to attend in the future.[42] Though most participants reported attending cervical screening (and wanted to continue attending), it became apparent during interviews that some women feared the appointment (eg, that it might trigger distressing memories and/or worried about the nurse's reaction if they behaved in an unexpected way during the test). Some women might have felt judged by the practice nurse or experienced significant pain during the test. The tool might, therefore, be helpful to women who have had a negative screening experience in helping to address their anxiety. For several women, there was no movement in their decision to accept or decline screening; some may need a separate intervention to help them.

Strengths and weaknesses of the research

To our knowledge, this is the first study to evaluate an informed-choice tool's impact on cervical screening decision-making for women with SMI.[56] Initial evidence has been gathered on the complexity of the decision-making process for some women living with SMI. The sample size was not powered to detect a statistically significant difference, as this study was designed to assess proof-of-concept only, therefore, findings should be interpreted cautiously. Nonetheless, the cohort was diverse in demographics, type of site (rural and inner city) and screening participation. Thus, findings are likely to apply to a wider population.

The quantitative study captured changes in participants' decision-making, but owing to the small sample size, the data could not illustrate the full impact that the tool may have had on participants. However, this limitation of the quantitative data was offset by including the interview data in the analysis. The qualitative data captured the tool's impact on some participants, such as how it may improve their future *experience* of screening or how it has improved their awareness of cervical cancer symptoms. For instance, though some women maintained their decision to attend screening before and after using the tool, they disclosed feeling more confident about attending their appointment, knowing what adjustments they could request. The qualitative data were, therefore, useful to support the interpretation of the quantitative data. A limitation of this study is the risk of social desirability bias.[87] This effect may have led to participants over-reporting past and/or future intentions regarding cervical screening attendance, possibly to avoid discussing why they refuse to attend cervical screening. Another limitation of the research lies in the fact that certain populations remained inaccessible during the development of the tool, such as service users on forensic and inpatient wards or people affected by homelessness, so the tool may not be acceptable or usable to them. Nonetheless, some study participants had spent time on inpatient wards, and health professionals who took part in this research work in multiple settings, so their perspectives may have partly offset this limitation.

Implications for practice

The principal implication for practice is that the tool may help women make an informed choice as to whether to attend cervical screening or not. As the tool addresses barriers to attendance, the tool may also translate into more women attending, thus saving lives and reducing the burden of needing cancer treatment.

This research has other specific implications for practice at different points of the cervical screening journey. Before the test appointment, the tool may inform how clinicians discuss screening uptake with their patients; for example, it might facilitate a discussion of why the patient is struggling to attend. The tool may also serve as a reminder/trigger to the health professional to discuss screening during a consultation. During the cervical screening appointment, if the patient shares these 'tick box pages' from the tool with health professionals, this may have influenced the way staff view screening, that is through the lens of someone who has a mental illness and/or had a traumatic experience. Having a better understanding of a patient's set of circumstances might, in turn, modify health professionals' behaviour towards other patients. The tool might also impact on how patients and professionals conducting the smear test interact during the screening appointment, for example, any words to avoid using or asking for a narrower speculum. Following the appointment, patients may feel more comfortable discussing their screening appointment with a member of their mental health support team. Service users may also feel more confident about asking their trusted mental health professional to accompany them to

the appointment. These implications for practice require further investigation.

The current UK government guidance[88] on *Support for people who find it hard to attend cervical screening due to having a mental health condition or having experienced trauma or abuse* is based on the present research. The tool is widely accessible to patients and clinicians via NHS Trust physical health portals, some local EMIS (Egton Medical Information Systems) portals and NHS websites such as the Northern Cancer Alliance[89] or third sector organisations.[90] However, printing costs can hinder its dissemination and visibility, and some people do not read leaflets but it could easily be adapted to another format. The tool has had international reach; the French National Cancer Institute has adapted the research to their national context.

Implications for research

The 'tick box' pages were an important feature of the tool for women with SMI and could act as a 'disclosure aid'; these could be adapted for other physical health checks such as dental appointments or hearing/eyesight tests. Whether the information contained in the leaflet in other formats, such as a mobile app, would increase its benefits could also be tested. Similar interventions for this population may be useful for other screening programmes. Though there is currently no national screening programme for lung cancer in the UK, the NHS has been offering 'Lung Health Checks' in some parts of England since autumn 2019.[91] Given the high rate of smoking among people with SMI, such an intervention may warrant further investigation.

It was unclear whether the tool enabled some women to make a more informed decision; more research is needed to ascertain whether the information provided in the tool improved their informed choice to attend or refuse screening.

The risk of reliving trauma by going for screening was deemed too great by some participants, so further research with this group on the acceptability of alternatives to a cervical swab, such as self-testing or urine sampling, is worth considering. For some women, the fear of receiving a cancer diagnosis was a factor in refusing to be screened; this group may need additional support to manage their anxiety. Some women with SMI who require further tests or oncological treatment following a cancer diagnosis may also need further support. High mortality rates from cancer in this group warrant exploring which interventions might be of value, since none specific to people with SMI are currently available. Trans men could not be reached, but research targeting cervical screening for this group is needed.

There are systemic barriers to accessing cervical screening pertaining to the healthcare system, which this tool could not address, such as being excluded from a GP practice or not receiving the invitation for screening if admitted to forensic services. How to overcome these barriers warrants further research. Training of health professionals (eg, nurses working in primary care and sexual health clinics) on barriers to screening in this group to reduce some of the stigmatising attitudes women with SMI may experience should also be investigated. A separate intervention using secondary care records to ensure women are not invited when they are unwell, for example, if they are in hospital, should also be explored. An NIHR-funded feasibility trial (OPTMISE—improving uptake of cervical screening in people with severe mental illness) is underway to explore whether the tool (and the accompanying video, which explains how the tool can be used) has an impact on uptake in this group of individuals who are overdue for cervical screening.[92] People with mental ill health, who have not responded to their last cervical screening invitation, will be sent either a text reminder that is usually sent by their GP or an enhanced text reminder with a link to the leaflet and video.

Lastly, the psychological impact on women with SMI testing positive for HPV deserves further investigation. The shift of cervical screening from an oncological to a communicable disease paradigm may create a novel barrier to cervical screening uptake for women with SMI. How this population of interest will react to receiving cervical screening results in the context of a positive or negative HPV test warrants further investigation.

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