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Predicting risk of psychosis in primary care: a qualitative study

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Abstract

Background

P Risk is a new tool which aims to help GPs identify people at risk of developing psychosis using electronic health record data of nonpsychotic symptom consultations, medications and sociodemographic factors.

Aim

To explore clinicians' and patients' views of the acceptability and usefulness of using P Risk in primary care.

Design and setting

Semi-structured interviews with GPs, Early Intervention (EI) team clinicians and patients from Bristol and London area.

Method

Three topic guides were developed to ensure consistency across interviews. Interviews were transcribed verbatim and analysed thematically.

Results

A total of 10 GPs, 6 EI clinicians, and 13 patients were interviewed. Most clinicians and patients welcomed the development of P Risk as a tool for improving the identification of people at risk of psychosis. However, some clinicians raised concerns about the quality of clinician coding in primary care medical records, availability of effective treatments, limited capacity of EI teams to work with people at risk, increased workload for GPs, and the negative impact on patients from being told about their risk of psychosis. For patients, identification of people at risk only made sense if there was treatment available. Interviewees said that clinicians should explain to patients what psychosis is, what it means to be at risk, which factors drive the risk, and how to address them.

Conclusion

Whilst most clinicians and patients welcomed the development of P Risk, there needs to be a clear pathway for assessing and offering treatment to those identified as being at risk.

Keywords

Risk, psychosis, primary care

How this fits in

- Identifying people at risk of psychosis in primary care is difficult.
- The P Risk algorithm uses electronic health record data of nonpsychotic symptoms, medications and sociodemographic factors, to inform GPs of a patient's risk of developing psychosis
- Telling someone that they may be at risk of psychosis should be communicated by a GP whom the patient knows and trusts. Patient communication should focus on what psychosis is, which are the modifiable factors that drive the risk and how to address them.

- There needs to be a clear pathway from assessing to offering treatment for people who are identified as being at risk.

Summary sentence:

P Risk provides an accurate, individual estimate of psychosis risk, but patient communication and care pathways are important considerations.

Introduction

Psychosis is a term which refers to a group of severe mental health illnesses characterised by episodes of loss of contact with reality. The outcomes of psychosis can be poor. Only one in seven individuals make a full recovery ((1), and in the UK, less than 10% of people with schizophrenia are employed (2).

Offering early treatment to people at risk of psychosis can decrease their risk of transitioning (3). NICE guidelines recommend that people at risk of psychosis are referred to Early Intervention (EI) for psychosis teams, or other specialist mental health services, and are offered cognitive behavioural therapy for psychosis (CBTp) with or without family intervention (4). EI teams were originally commissioned to offer specialized support to people experiencing their first episode of psychosis, but more recently approximately half of the EI teams in England have also offered treatment (mostly CBTp) to people at risk of psychosis (5).

GPs are usually the first point of contact for patients with mental health problems, and they play a key role in referring patients to secondary care. However, identifying people at risk in primary care is difficult. Possible reasons include: (1) the early symptoms of psychosis are non-specific, (2) most GPs do not develop diagnostic skills for identifying these patients as, individually, they see few cases per year; and (3) patients do not always have continuity of care with the same GP, so subtle changes in their mental state are sometimes missed.

Sullivan et al., (2022, 2024) have developed an algorithm, called P Risk, which aims to help GPs identify people at risk of psychosis. P Risk uses electronic health record data of nonpsychotic symptoms and signs (consultations for suicidal behaviour, depression/anxiety, substance abuse, history of consultations for suicidal behaviour, smoking history and prescribed medications for depression/anxiety/PTSD/OCD and total number of consultations), and sociodemographic factors (age, sex, ethnicity and social deprivation) to identify people at risk of developing psychosis over the next five years. P Risk has good discriminative accuracy (Harrell's C statistic of 0.78, meaning that it can correctly discriminate between those who will and will not develop psychosis in 78% of cases). However, for P Risk to be used in practice, it needs to be acceptable and relevant to practitioners and patients.

This study aimed to explore clinicians' and patients' views of the acceptability and usefulness of using P Risk in primary care.

Method

Interviews were held with GPs, EI clinicians and patients. We interviewed (1) GPs as they play a crucial role in referring patients to secondary care services; (2) EI clinicians as, according to

NICE guidelines, patients at risk should be assessed by, and offered treatment in EI teams (4); and (3) patients as P Risk uses patients' health record data.

Recruitment and sampling

GP recruitment. GP practices in Bristol and London were informed about the study via local Clinical Research Networks (CRNs). Each GP practice was asked to help with recruiting one or two GPs for the qualitative interviews. Eight Bristol practices originally expressed an interest, of which five signed a collaboration agreement. The other three practices either stopped replying or informed us that they were no longer able to support the study. Four London practices expressed interest and signed the collaboration agreement.

EI recruitment. EI clinicians from four mental health trusts (one in Bristol and three in London) were informed about the study via their local CRNs. EI clinicians from three trusts expressed an interest in being interviewed.

Patient recruitment. Patients were recruited via the same GP practices involved in GP recruitment. To be eligible, patients had to be 18 years or over in age, and have consulted their GP for non-psychotic mental health problems over the past six months. Eligible patients were invited by their practice to take part in the study via a text which included a link to the study webpage. Prior to sending out the text message, the list of eligible patients was reviewed by a local GP. Patients who were interested were asked to complete a form that indicated this, and return it to the researcher. The researcher contacted patients who were interested to answer questions and arrange a convenient date/time for the interview.

The original plan was that we would also interview carers. However, we were not able to identify any carers, as patients either reported that they had no carer, or said they would ask their carer for permission to pass on their contact details to the study team, but we did not hear back from them.

The study received ethical approval from North West – Greater Manchester (GM) East on 15/03/2023 (Reference number 22/NW/0289).

Data collection

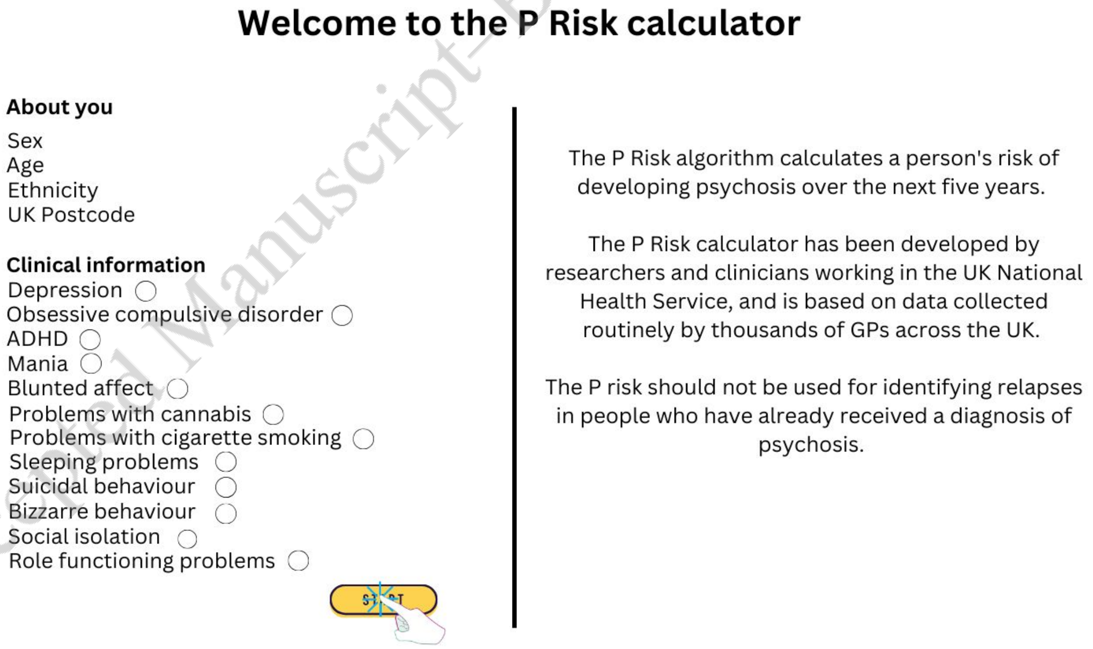
Topic guides were used to ensure consistency across interviews. Two topic clinician guides (GP and EI clinician) and one patient guide were developed in parallel to ensure key areas were included in each. They were based on the aims of the research and developed through discussion with team members.

The clinician guide included questions about the current identification and management of patients at risk, advantages and disadvantages of using P Risk, patient communication and treatment. The patient topic guide included questions about patients' views of GPs using P Risk, and patient communication and treatment.

Verbal consent to take part in the study and to audio-record the interviews was obtained from interviewees immediately prior to interview. Interviews were conducted by DS, a researcher experienced in mixed-method psychosis research. The interviews were held via video-conferencing, to allow the interviewer to present interviewees with a prototype of P Risk.

At the start of the interview, the researcher shared their screen with the interviewee, and showed them the P Risk prototype. The prototype illustrated the predictors used by the algorithm to calculate someone's risk of psychosis (Figure 1.1). The researcher explained that the algorithm would run on GPs' computers, and automatically calculate someone's risk when GPs entered a code for a nonpsychotic mental health problem. It was explained that the GP would then be prompted to ask additional psychosis-relevant questions to patients who were identified as being at risk (Figure 1.2).

Figure 1.1. An illustration of the P Risk prototype as shown to interviewees.



Welcome to the P Risk calculator

About you

Sex
Age
Ethnicity
UK Postcode

Clinical information

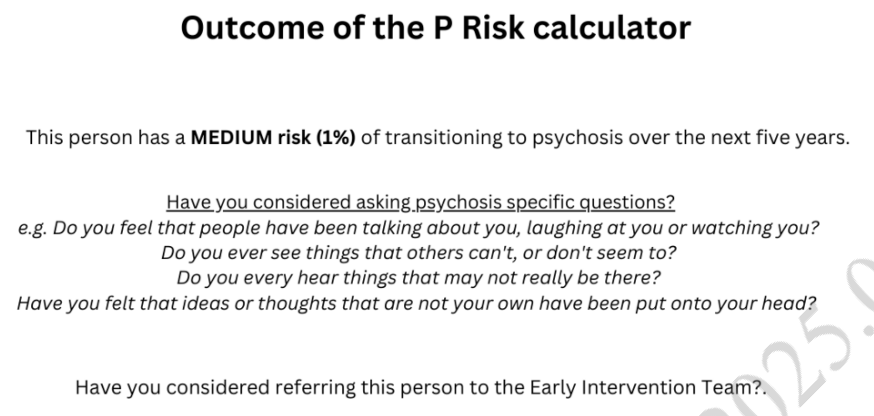
Depression ○
Obsessive compulsive disorder ○
ADHD ○
Mania ○
Blunted affect ○
Problems with cannabis ○
Problems with cigarette smoking ○
Sleeping problems ○
Suicidal behaviour ○
Bizzarre behaviour ○
Social isolation ○
Role functioning problems ○

The P Risk algorithm calculates a person's risk of developing psychosis over the next five years.

The P Risk calculator has been developed by researchers and clinicians working in the UK National Health Service, and is based on data collected routinely by thousands of GPs across the UK.

The P risk should not be used for identifying relapses in people who have already received a diagnosis of psychosis.

Figure 1.2. An example of the outcome of P Risk as shown to interviewees



Outcome of the P Risk calculator

This person has a **MEDIUM risk (1%)** of transitioning to psychosis over the next five years.

Have you considered asking psychosis specific questions?
e.g. Do you feel that people have been talking about you, laughing at you or watching you?
Do you ever see things that others can't, or don't seem to?
Do you every hear things that may not really be there?
Have you felt that ideas or thoughts that are not your own have been put onto your head?

Have you considered referring this person to the Early Intervention Team?.

Data analyses

All interviews were transcribed verbatim (except for one patient interview which was poorly recorded and where the interviewer took notes), and analysed thematically (8). Analysis entailed KT and DS independently reading and manually coding a sample of transcripts according to codes they had developed inductively. KT and DS then met to compare their coding, and create one coding frame for each set of interviews. These coding frames were then independently applied to another sample of transcripts, and new codes were added as needed. KT and DS then met again to discuss their coding, which resulted in further codes being added or existing codes being clarified. When the coding frames were finalised, all transcripts were uploaded to NVivo and coded electronically. Data under specific codes were then retrieved and summarised in tables to enable researchers to look across and within the interviews, and to highlight common themes and deviant cases. Each data set was analysed independently before findings were compared across them. Findings were also discussed with other researchers and primary care clinicians in our team.

Public and Patient Involvement (PPI)

This research question originated from a series of psychosis service user (SU) forum events where SUs described problems they had experienced getting their GP to recognize warning symptoms of psychosis. Prior to our funding application, we have held two virtual PPI events with 13 attendees from across the UK, with lived experience of psychosis or of caring for someone with psychosis. PPI's input has directly informed development of the study. After receiving funding for the study, a new PPI group (which was comprised of 6 people) has further reviewed the patient-facing study documentation.

Results

Characteristics of clinicians and patients

In total, we interviewed 10 GPs, 6 EI clinicians, and 13 patients. Clinicians were interviewed between May and November 2023, and patients between August and December 2023. On average (mean), GP interviews lasted 23 minutes, EI clinician 27 minutes, and patient interviews 25 minutes.

Four (40%) GPs, four (67%) EI clinicians and 10 (77%) patients were from Bristol area. Seven (70%) GPs, four (67%) EI clinicians and 10 (77%) patients were female. Mean age of GPs was 42.4 years (SD 7.9), EI clinicians 49.5 years (SD 12.1) and patients 39.7 years (age range 20 to 69 years; SD 15.3).

Of the GPs interviewed, one had an intercalated degree in psychology, and two of them said they saw a high number of patients with mental health problems. The mean duration of working as a GP was 11.1 years (SD 6.3). Of the EI clinicians, two were consultant psychiatrists, two were specialty registrars in psychiatry, one was a senior practitioner, and one was a mental health nurse.

Of the patients interviewed, three (23%) were of an ethnic minority background.

Table 1. Demographic characteristics of interviewees

	Number of interviewees per site			Age (mean (SD))	Female (%)
	Total N	Bristol (N (%))	London N (%))		
GPs	10	4 (40%)	6 (60%)	42.4 (7.9)	7 (70%)
EI clinicians	6	4 (67%)	2 (33%)	49.5 (12.1)	4 (67%)
Patients	13	10 (77%)	3 (23%)	39.7 (15.3)	10 (77%)

Findings

The main themes were i) advantages and disadvantages of using P Risk in primary care; and (2) patient communication. Quotes have been tagged to denote the specific group (GP, EI and P (for patient)), and research site (L for London, and B for Bristol).

GPs' views

Advantages and disadvantages of P Risk

Most GPs said that P Risk would be a valuable tool as it would raise their awareness of patients at risk, especially in those with subtle presentations or those consulting for common mental health illnesses.

> *It could make you think about psychosis … in patients you may not have thought about before. So sometimes in less severe depression … with some occasional cannabis use in someone who's quite chatty, orientated … you might not think to screen for psychosis. (GP L2)*

A couple of GPs also said that P Risk would help them quantify an instinct, which would then be helpful in initiating a discussion about psychosis with the patient. Some GPs also mentioned that people at risk could be offered treatment which would target their risk factors (e.g. cannabis use), and thus prevent transition to psychosis.

When we asked GPs if they would trust the P Risk score, some GPs said that they would need to know which were the factors that drove the individual risk, and emphasized that P Risk should not replace clinical judgement. Some GPs raised concerns about the quality of coding or mentioned that they had never coded for some of the predictors used by P Risk.

Some GPs also said that P Risk might prompt them to screen for psychosis in patients who did not need to be screened, and mentioned that there may not be sufficient resources to manage the additional work. Several GPs also raised concerns that were related to the availability of effective treatment for people at risk, EI teams' capacity to offer treatment, and patients' willingness to engage with it.

> *Are there any evidence-based interventions that have been shown to reduce the risk … if we can't do anything about it then is it worth screening people for? (GP L4)*

Patient/carer communication

We asked GPs when and how patients should be told that they were at risk. GPs' views varied. Whilst some GPs said that patients should be told this in the original consultation ('*you don't want to make it a massive thing that you need to prepare them for' (GP B3))*, others said that patients should be communicated this in a follow-up consultation, especially if patients were already suffering from depression or anxiety. However, one GP said that it would not be helpful to tell people they were at risk, and suggested that, instead, patients should be told how to improve their wellbeing (e.g. good sleep, absence of drug use).

> *Absolutely not … that thing about understanding yourself as a ticking time bomb, if you're already feeling anxious … telling someone their risk of developing psychotic phenomena, it's a bit like telling everybody in their fifties or sixties they're at risk of developing cancer, do I really need to think about that very much? Not sure I do. (GP L1)*

In terms of communication strategies, most GPs said that people should first be told what psychosis is, and signposted to written information. There should also be a focus on the modifiable factors that drove the risk, and how patients could decrease their risk. Given the sensitivity of the topic, some GPs said that this conversation should be carried out by a GP whom the patient knows and trusts.

<u>EI clinicians' views of P Risk</u>

Advantages and disadvantages

From EI clinicians' perspective, P Risk would be especially helpful in improving identification of people with insidious signs of psychosis.

> *The blatantly obvious stuff gets in quite easily, but I think sometimes the more subtle stuff gets missed and we lose an opportunity to support people early on. (EI B3)*

EI clinicians also said that P Risk could make the risk of psychosis more real to people, and help GPs explain to people how to decrease their risk.

> *They [GPs] could … tell them [patients] 'Look your cannabis use puts your risk at 13% and if we take cannabis use out of the picture your risk is down to 6%'. (EI B4)*

Some EI clinicians mentioned that, although not all EI services were commissioned to work with people at risk, developing a tool which would improve patient identification should not depend on the current commissioning situation, as this may change. Furthermore, some EI clinicians said that P Risk may improve the referral rates to EI teams, which could then help them build an argument for commissioning their services to work with these patients.

> *If there is a substantive amount of ARMS [at risk mental state] type of patients … it might be that … we would become commissioned for this specific ARMS patient group … it would be very helpful … because some of those patients are our future patients anyway (EI B2)*

However, some EI clinicians said that, as the predictors of P Risk were quite common, it might flag up a high number of people and potentially overwhelm the EI services. Some EI clinicians also raised concerns about the quality of coding in primary care medical records, and potential discrepancies between GPs' and secondary care clinicians' use of terms describing mental health conditions (e.g. mania). The reliability of P Risk could also be negatively impacted by patients inaccurately reporting their drug use, or P Risk not differentiating between those with a small/infrequent versus high/daily use of drugs. One EI clinician further said that P Risk did not account for the severity of past episodes of illness, people's insight, compliance with treatment, and the protective factors against psychosis.

Patient communication from an EI perspective

Most clinicians said that patients should be told about their risk before being referred to secondary care. The exact timing would depend on GP's relationship with the patient, and whether the patient was help-seeking.

Most EI clinicians stressed the importance of not frightening people when discussing their risk, explaining them how to minimise the risk, and where to seek help.

> *It's important that it is conveyed in that positive way where people can say 'Look, we've looked at something that's a moveable feast here that if you do something about these factors … maybe you can reduce that'. (EI B1)*

It should be further explained that P Risk assesses someone's probability of developing psychosis, and some of those identified may never develop psychosis.

> *It's trying to put it within that context of that this is about probability, this is about something that might happen and not something that will definitely happen (EI B1)*

Patients' views of P Risk

Overall, patients welcomed the development of P Risk as it would prompt GPs to screen for psychosis as, in their view, GPs may have limited expertise in identifying people at risk.

> *I think it sounds really good … as someone who's struggled with mental health issues most of my life … GPs are … general practitioners and they're not like experts in the field … it's a bit of reassurance that there's like a little prompt for them to think about those kind of things. (P B4)*

A couple of patients also mentioned that P Risk could motivate patients to address some of the risk factors for psychosis. However, like practitioners, patients linked the value of P Risk to treatment availability, arguing its value depended upon whether the patient could access treatment.

> *It's great that GPs would be able to identify … early signs and then be able to refer them to a service … but only provided that that service is there and actually fully funded and available for that person (P B3)*

Nevertheless, one patient said that even in the context of limited treatment availability, it would still be worth developing a tool which would improve patient identification, as 'y*ou've got to start somewhere' (P B1).*

When we asked patients about their concerns for using P Risk, some mentioned the reliability of the tool, the length of time it had been tested for, the possibility of over-diagnosing people, and P Risk not considering symptom severity. Patients also said that P Risk should be used by a GP who knows the patient and is able to assess symptoms in their context.

Furthermore, some patients were concerned about how GPs would initiate a discussion about psychosis with a patient who consulted for a different problem, and mentioned that GPs should explain to the patient why they were asked psychosis-specific questions.

Patient communication

We asked patients how helpful it would be to tell someone they were at risk. Most patients said that this would depend on the individual, and whether the risk factors were modifiable.

> *It's helpful if there's things you can do to mitigate the risk. If there isn't, then potentially you're just kind of scaring a patient (P B3)*

Patients further explained that whilst telling someone they were at risk would create worry, if treatment was available and the risk factors were modifiable, then they would like to know about it.

In terms of communication strategies, most patients said that clinicians '*have got to be careful not to scare the patient to death' (P B1)*. Patients also said that clinicians should not use the word psychosis, as it is associated with danger. Instead, it would be better if clinicians would focus on symptoms and their impact.

> *I think psychosis is … a loaded term for a lot of people … that sounds similar to psycho … like think of serial killers … maybe using another term … having that be phrased in a way which just talks about the symptoms … and how that would affect the person. (P B1)*

In addition, patients said that it would be helpful if clinicians could explain to patients why they had been identified as at risk, what factors drove their risk, what treatment was available and how effective the treatment was. Furthermore, GPs should emphasize that being at risk did not mean the patient would definitely develop psychosis.

> *The emphasis needs to be on the additional help that would be provided … it needs to be made clear … it's an additional risk and it's not a definite, you're not definitely going to experience psychosis. (P B4)*

Patients' views varied with regards to when the GP should tell people they were at risk, but most stressed the importance of knowing and trusting the GP who communicated this. However, a couple of patients of an ethnic minority background said that it should not be the GP, but the mental health specialist who should communicate this to the patient, and only after it had been confirmed that the patient was at risk. Furthermore, some patients said that people should only be told they were at risk if the risk was very high.

Discussion

Summary

Most GPs and EI clinicians said that P Risk would be a valuable tool for improving identification of people at risk, especially of those with subtle clinical presentations. They thought patients identified could be offered treatment which would target their risk factors, and potentially prevent transition to psychosis. Overall, patients were positive about the use of P Risk, although, for them, the value of identification was directly related to provision of treatment.

GPs and EI clinicians raised concerns about the quality of coding in primary care records and its potential impact on the reliability of the tool. Some GPs also raised concerns related to the availability of effective treatments, patients' willingness to engage with treatment, and limited capacity of EI teams to work with these patients. However, most EI clinicians were not very concerned about their capacity. On the contrary, some of them thought an increase in the number of referrals may contribute towards the commissioning of EI teams to work with a high-risk patient group.

Most patients and clinicians said that telling someone they were at risk was a sensitive issue, which should be communicated by a GP whom the patient knows and trusts. Clinicians should tell patients what psychosis is, what it means to be at risk, what modifiable factors drive the risk, and how to address them.

Strengths and limitations

EI clinicians had a range of clinical experience and expertise (i.e. psychiatrists and mental health nurses), and worked in areas where EI teams were or were not funded to work with those at risk. With hindsight, it might have been helpful to also interview psychologists as they play an important role in providing talking therapies to people at risk. Patient interviewees were male and female, from a range of GP practices and EI teams from Bristol and London area. However, we acknowledge that the GP practices, EI teams and individual clinicians and patients who were interviewed were self-selecting, and may have had an interest in psychosis, which might have biased our findings.

All interviews were conducted via video-conferencing, and the richness of data collected indicates that online interviews can gather the same material as those conducted in-person (9). The clinician and topic guides covered the same areas, which allowed us to compare clinicians' and patients' views. Internal bias in data analysis was minimised by double coding a sample of the interviews and discussing findings with other researchers and primary care clinicians.

Most patients interviewed defined themselves as white British. We would like to have interviewed more people from an ethnic minority background, especially as in Western countries psychosis is more common in some ethnic minority groups compared to the white majority (10). Similarly, we would like to have interviewed more males, as males are usually at higher risk of psychotic disorders compared to females (11).

Another limitation is that we were unable to interview any carers as it had been originally planned. However, this is an important finding in itself, as it shows that some people who consulted their GP for non-psychotic mental health problems did not have any carers, or it is possible that some patients might not feel comfortable to discuss mental health issues with family members.

Comparison with existing literature

The difficulty of identifying people at risk has been discussed in many research studies (12–16). A recent meta-analysis signalled the need for developing screening instruments that would take into account the non-psychotic symptoms, as they are often missed by GPs (17). For example, it has been shown that whilst GPs feel quite confident identifying the positive symptoms of psychosis (delusions, hallucinations), they may miss the non-specific symptoms, such as low mood or decreased social functioning (17).

Consistent with our findings, other studies have also shown that people who consulted for common mental health symptoms may not always be screened for psychosis (16,18,19), hence the importance of P Risk in identifying less obvious cases. Similar to other studies which highlighted the complexity of coding in primary care (20), clinicians in our study raised concerns about the quality of coding, and its potential impact on the reliability of P Risk. It is reassuring that P Risk was developed and validated on large datasets of UK primary care data (CPRD), and has good psychometric properties (6,7).

As signalled by most participants in our study, identifying people at risk has to be accompanied by the provision of effective treatments. Whilst CBT for psychosis is an effective treatment for people at risk (3,21,22), which is currently recommended by NICE guidelines (4), not all people at risk have access to this treatment. For example, in England, only ~50% of the EI teams are funded to work with these patients (5). We acknowledge this is a complex situation, and believe that, whilst identifying people at risk is important, there needs to be a clear pathway for assessment and treatment, especially in those EI teams which are not funded to work with patients at risk. It is therefore important to further explore other services which may offer help to the high-risk group, such as the Talking Therapy services, the Drug and Alcohol Services or charity organisations.

Most patients in our study emphasised that telling someone they are at risk is alarming and must be handled sensitively. Several studies have discussed how societal conceptions about psychosis can lead to self-stigma, fear and negative coping behaviours, which can delay the disclosure of symptoms and acceptance of treatments (23–25). It has also been suggested that telling people about their psychosis risk may have both positive (i.e. greater self-understanding, instilling hope that there is a way forward) and negative implications (internalization of negative stereotypes about psychosis, fear about how they may be viewed by others) (26). Good communication is therefore essential when communicating risk to patients. Whilst we are not aware of any studies which have examined the effectiveness of different ways of communicating psychosis risk, it has been suggested that asking people what it means for them to be identified as being at risk, would be important (26). In addition, similar to other studies (27), our interviewees mentioned that risk for psychosis should only be communicated by a clinician whom the patient knows and trusts.

Furthermore, our findings are in line with results of a recent study which showed that patient communication should be personalised (28). As P Risk provides clinicians with information about which factors drive an individual's risk score, they can personalise information and discuss with the patient their personal risk factors and how to address them. Interestingly, a review which aimed to examine the efficacy of personalised risk estimates in changing health related behaviours (e.g. smoking, diet) suggested that the impact of communicating risk information could be much higher if clinicians addressed people's self-efficacy (i.e. perceived capacity to implement certain changes) and response efficacy (i.e. the belief that a certain behaviour will reduce a certain threat) (29).

Implications for research and/or practice

Most interviewees welcomed the development of P Risk as it would help GPs identify the early symptoms of psychosis which may otherwise go unnoticed. However, it is crucial that GPs are offered guidance regarding the pathway for assessing and offering treatment to those identified. Future research should examine methods for communicating risk of psychosis to patients (ideally by comparing novel communication strategies with treatment as usual), explore strategies for dealing with the modifiable risk factors, and examine the best management approach, which may be different for people at medium versus high risk. Future research should then further examine the feasibility of implementing P Risk in real life situations. If P Risk is shown to be valid and acceptable for use in real life situation, then clinical services need to adapt their criteria in response to P Risk, so that people identified as being at risk would be offered adequate support and treatment.

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Ethical approval

Ethical approval for the study was given by North West – Greater Manchester (GM) East on 15/03/2023 (Reference number 22/NW/0289).

Competing interests

The authors declare no conflict of interests.

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