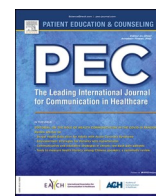


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Motivations and experiences of high-risk men in risk-adapted prostate cancer early detection: A qualitative study

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ABSTRACT

Objective: Men with a family history of prostate cancer (PCa) or a pathogenic germline variant (PGV) face increased PCa risk. However, structured PCa early detection and insights into the experiences of affected men remain limited. This qualitative analysis explored (i) why men with familial or genetic PCa risk attended a risk-adapted prevention clinic, (ii) which elements they found helpful, and (iii) how early detection services could be tailored to their needs.

Methods: This study was part of the psychosocial mixed-methods study *ProFam-Psych*, run alongside the *ProFam-Risk* prevention clinic. Semi-structured interviews were conducted in a subgroup (13/86 study participants). The clinic offered PSA testing, mpMRI, genetic counselling and panel testing followed by risk-adapted recommendations. Participants were men without PCa who had a family history or previously detected PGV, and men with PCa who had a family history. Participants were selected using maximum variation sampling. Data were analysed by two researchers using Kuckartz's qualitative content analysis.

Results: Seven motivators were identified: (1) clarify risk/PGV status, (2) information needs, (3) benefits for the family, (4) support others, (5) external recommendation, (6) access to structured screening, and (7) preventive recommendations. Participants with a family history were primarily motivated by (1) and (3), men with PGVs by (5) and (6), with (6) and (7) unique to this group. Perceptions of elements most helpful to participants varied, but

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the integrated setting with time for questions, clear guidance, and a reliable point of contact was valued. Suggested improvements were mostly organisational, including reminder systems to support long-term adherence. **Conclusion:** Interdisciplinary early detection for PCa was accepted by participants, with motivators such as screening access and information needs highlighting the need for the implementation of structured screening programs for high-risk men.

Practice implications: Results may inform future outreach efforts and design of screening strategies for familial and genetic PCa risk.

Trial and protocol registration: DRKS.de, DRKS00032350. Prospectively registered with the German Clinical Trials Register (DRKS) on 14 September, 2023

Selected heading: Patient and User Perspectives and Characteristics

1. Introduction

Prostate cancer (PCa) is one of the most heritable malignancies, with an estimated 57% of disease risk attributed to inherited genetic factors [1]. A family history of PCa and relevant pathogenic germline variants (PGVs) have been associated with a substantially elevated PCa risk, and more adverse clinical outcomes [2–5]. The identification of individuals with elevated PCa risk is therefore crucial to enable timely screening, diagnosis, and treatment [6].

Current clinical guidelines recommend risk-adapted early detection strategies and genetic testing for men at elevated PCa risk [7–9]. However, clear pathways for genetic testing and risk-adapted strategies are well established for breast and ovarian cancer, but limited for PCa [7, 10]. Awareness of genetic testing in PCa patients is low and cascade testing of at-risk male relatives is rarely initiated [11–13]. The low uptake of genetic testing for PCa has been attributed to a lack of awareness and access to risk-related information, as well as an underrepresentation of men in clinical trials [13–18]. Moreover, the low uptake stands in contrast with high levels of interest reported both in healthy men and men with PCa who have a family history [19,20].

Therefore, a clear understanding of motivators, experiences and needs of men at elevated PCa risk is required for a successful implementation of early detection structures [21]. Referring to the Health Action Process Approach (HAPA), motivation for health behaviour is based on risk perception, outcome expectancies and perception of self-efficacy [22]. Prior studies in men at risk of BRCA PGVs and in a genetic-risk profiling study have identified key motivators for genetic testing, including protection of the family, social encouragement, personal interest in information, positive expectations, self-efficacy, and contribution to research [14,18,23,24]. However, assessments of men's experiences within interdisciplinary PCa early detection programmes remain limited.

To address the need for risk assessment and risk-adapted early detection structures for men at elevated PCa risk, the first German PCa prevention clinic (*ProFam-Risk*) was established at the University Hospital Düsseldorf (UKD) [25]. The interdisciplinary clinic provides genetic counselling and testing, urological examinations including prostate-specific antigen (PSA) testing, multiparametric magnetic resonance imaging (mpMRI), and family history assessment. Patients receive individualised PCa screening recommendations regarding PSA and mpMRI screening.

In order to adapt prevention strategies to participants' needs, the present qualitative analysis explores men's perspectives on risk-assessment and early detection within a high-risk prevention clinic. It examined: i) why men chose to participate in a risk-adapted prevention clinic; ii) which elements and procedures of risk assessment and risk-adapted prevention were perceived as particularly helpful; and iii) how early detection services can be further optimised to the needs of those seeking preventive care.

2. Methods

This methods section follows the Standards for Reporting Qualitative Research (SRQR; [26]).

2.1. Study design and setting

This study is part of the prospective, non-interventional, longitudinal, mixed-methods study *ProFam-Psych*, which quantitatively assesses the trajectories of psychosocial outcomes in men attending the prevention clinic at 4 time-points [27]. Within the scope of the current qualitative study, semi-structured interviews were conducted after participants had received their test results and their PCa screening recommendations (Fig. 1).

The prevention clinic was established in March 2023 and is a cooperation between the Department of Urology, the Institute of Human Genetics, the Center for Familial Breast and Ovarian Cancer, the Clinical Institute of Psychosomatic Medicine and Psychotherapy and the Department of Diagnostic and Interventional Radiology at the UKD [25].

Participants consisted of three groups: Group 1 = Men without PCa who had a family history of PCa; Group 2 = Men without PCa who had a previously detected PGV associated with PCa risk; Group 3 = Men with previous or current PCa who had either a family history of PCa or a detected PGV (see [25]). The undertaken procedures within the prevention clinic were adapted to each group (Table 1).

2.2. Ethical aspects

Within their enrolment in the *ProFam-Psych* study, participants consented to be contacted for the qualitative interviews and additional written informed consent was obtained prior to the interviews. The study was approved by the ethics committee at the Medical Faculty of the Heinrich-Heine-University Düsseldorf (2023–2551; 13 September 2023).

2.3. Participant selection

Eligibility criteria:

For healthy men (without PCa):

- ≥ 2 first-degree relatives with PCa diagnosed at any age and own age ≥ 40 years, OR
- ≥ 1 first-degree relative with early-onset PCa (< 60 years) and own age ≥ 40 years, OR
- presence of a PGV associated with PCa risk.

For men with previous/current PCa:

- ≥ 1 first-degree relative with PCa, OR
- presence of a PGV associated with PCa risk.

Individuals with insufficient German language skills or disorders that prevented independent participation (e.g. neurological) were excluded from the *ProFam-Psych* study. During study recruitment, the eligibility criterion for men with PCa was adjusted to require only one first-degree relative with PCa, in accordance with the updated German S3 Guidelines for Prostate Cancer [7]. An ethics amendment was submitted and approved accordingly.

Participants were recruited via telephone, with the aim of enrolling a

similar number of individuals from each of the groups. In Group 3, we aimed to include participants undergoing active surveillance as well as those with previous/current active treatment. Participants were selected using maximum variation sampling to ensure the greatest possible diversity in terms of sociodemographic and clinical characteristics (age, marital/family status, newly diagnosed cancer or identified PGV) [28]. All interviews were completed before formal coding. The research team monitored the emergence of novel perspectives after each interview. Saturation and stability of the category system were assessed during the coding process, with the final interviews confirming the established analytic framework.

2.4. Data collection

Semi-structured interviews were conducted between April 2024 and March 2025 via telephone or face-to-face. Face-to-face interviews took place in a dedicated interviewing room at the UKD. All interviews were conducted by the first author (MKK), a female psychologist with in-depth knowledge of PCa early detection. After each interview, the interviewer used a memo sheet to record reflections and impressions, including observations regarding the participant’s level of comfort (e.g., hesitant responses). Given the gendered context of PCa, a potential influence of the interviewer’s gender on dynamics cannot be precluded. For consistency, an interview guide was used. Particularly sensitive topics, such as incontinence and erectile dysfunction, were not part of

the interview guide and only discussed when raised by participants. The interview guide was designed to cover a broader range of topics than those reported in this analysis (see Appendix). Key themes included reasons for participation, expectations, personal understanding of genetics and heredity in relation to PCa, experiences with the procedures, personal and social impact, and overall assessment of the clinic. Questions were tailored to the procedures relevant to each group.

2.5. Data analysis

All interviews were audio-recorded, transcribed using a transcription software (f4transkript, 2024), de-identified and proofread by author IB. Data were analysed by the authors MKK and IB using the data analysis software MAXQDA [29]. Qualitative content analysis according to Kuckartz was applied, as the objective of this study was to describe and categorise the reported experiences by participants while also allowing the incorporation of deductive categories from existing literature [30].

The analysis followed a multi-stage process and included a deductive-inductive mixed form of category development: (1) an initial hierarchical code frame was deductively developed based on relevant literature [23,31–41] and the interview guide; (2) three interviews were independently coded by MKK and IB, followed by comparison, discussion, and refinement of the coding frame with inductive additions; (3) step 2 was repeated with three additional interviews, (4) after the coding frame was saturated, all interviews were divided between MKK and IB,

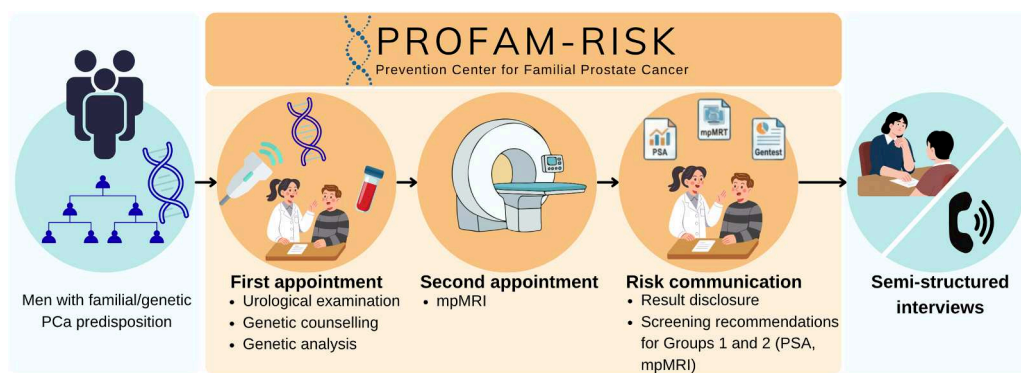


Fig. 1. Study timeline. Enrolment into the ProFam-Psych study took place upon the first appointment at the ProFam-Risk prevention clinic. Participants with current or previous PCa did not receive screening recommendations, as they were already undergoing routine aftercare. Group 1 = Men without PCa who had a family history of PCa; Group 2 = Men without PCa who had a previously detected pathogenic germline variant associated with PCa risk; PCa = Prostate Cancer; mpMRI = Multiparametric magnetic resonance imaging; PSA = Prostate-specific antigen.

Table 1 Detailed procedures at the ProFam-Risk prevention clinic.

Group	Urological examination	Radiological examination	Genetic examination
1	<ul style="list-style-type: none"> • medical exam • PSA test • sonography (as indicated) • urological counselling 	mpMRI	<ul style="list-style-type: none"> • genetic counselling including pedigree analysis • genetic testing using a panel of 20 genes associated with PCa risk
2	<ul style="list-style-type: none"> • medical exam • PSA test • sonography (as indicated) • urological counselling 	mpMRI	<ul style="list-style-type: none"> • genetic counselling upon request (prior genetic counselling had been performed externally) • no genetic examination (as participants had been previously tested)
3 Without previous genetic testing Known PGV	<ul style="list-style-type: none"> • PCa aftercare within usual care • urological counselling • PCa aftercare within usual care • urological counselling 	usual care	<ul style="list-style-type: none"> • genetic counselling including pedigree analysis • genetic testing using a panel of 20 genes associated with PCa risk • genetic counselling upon request (prior genetic counselling had been performed externally) • no genetic examination (as participants had been previously tested)

Table adapted from [27]. The genetic panel included the following pathogenic germline variant genes: *ATM, BRCA1, BRCA2, EPCAM, HOXB13, MLH1, MSH2, MSH6, PMS2, TP53, NBN, CHEK2, ATR, BRIP1, FANCA, GEN1, PALB2, PTEN, RAD51C, RAD51D*. Group 1 = Men without PCa who had a family history of PCa; Group 2 = Men without PCa who had a previously detected PGV associated with PCa risk; Group 3 = Men with previous or current PCa who had either a family history of PCa or a relevant PGV.

PSA = Prostate-specific antigen; mpMRI = Multiparametric magnetic resonance imaging; PCa = Prostate cancer.

independently coded, and cross-checked; (5) discrepancies were discussed until consensus was achieved. Ongoing discussions enhanced coding consistency and allowed for critical reflection on potential researcher bias.

Baseline sociodemographic data were collected quantitatively before the first appointment and analysed using the statistical software R [42].

3. Results

3.1. Participants

Data from 13 participants were included in the analysis: two from Group 1 (men without PCa who had a family history), six from Group 2 (men without PCa who had a previously detected PGV), and five from Group 3 (men with PCa who had a family history; 2 under active surveillance). No participants in Group 3 had previously undergone genetic testing. Two additional participants were excluded due to screening failures.

Ten participants had been invited to the prevention clinic by the hospital, two had been referred by clinicians, and one learned about it through family. Baseline sociodemographic characteristics are presented in Table 2 (see Appendix for further details). During clinic attendance, one participant was newly diagnosed with intermediate-risk PCa, and another was found to carry a PGV not associated with PCa risk.

Table 2
Baseline characteristics of participants.

Characteristic	N/ Mean	%/Range
Age (Mean; Range)	53	28–73
Marital status		
Married	8	61.5
Married and living separately	1	7.7
In a partnership	2	15.4
Widowed	1	7.7
Single	1	7.7
Education Level		
ISCED Level 3: Upper secondary education	2	15.4
ISCED Level 4: Post-secondary non-tertiary education	1	7.7
ISCED Level 6: Bachelor's or equivalent level	4	30.8
ISCED Level 7: Master's or equivalent level	5	38.5
ISCED Level 8: Doctoral or equivalent level	1	7.7
Employment		
Full-time	8	61.5
Pensioner	5	38.5
Children (Yes)	10	76.9
Sons (Yes)	8	61.5
Net household income		
2.500 - > 3.500	3	23.1
3.500 - > 4.500	2	15.4
4.500 - > 5.500	2	15.4
5.500 - > 7.500	3	23.1
7.500 - > 10.000	2	15.4
10.000 - > 18.000	1	7.7
Native language		
German	12	92.3
English	1	7.7
Cancer diagnoses (multiple entries possible)	6	46.2
Prostate cancer	5	38.5
Time since prostate cancer diagnosis in months ^a (Mean; Range)	64.8	5–172
Bladder cancer ^b	2	15.4
Pathogenic germline variant	6	46.2
BRCA1	4	30.8
BRCA2	1	7.7
MSH2	1	7.7
Mental health characteristics		
Depression	1	7.7

ISCED 2011 = International Standard Classification of Education 2011 [43].

^aTime of diagnosis was only available as month/year; for one participant, only the year of diagnosis was known, therefore, the month was set to June of that year ^bOne participant reported prostate and bladder cancer.

Interviews lasted on average 45 min (range: 29–77 min), with seven interviews conducted face-to-face and six via telephone.

3.2. AIM I: Motivators for participation

The first category captured participants' motivations and expectations regarding their decision to attend the prevention clinic. An overview of all categories and quotes is provided in the Appendix.

3.2.1. Motivators across groups

Clarify risk and pathogenic germline variant status

All participants of Group 1 (men without PCa who had a family history), and Group 3 (men with PCa who had a family history), and a subgroup of Group 2 (men without PCa who had a PGV) reported this motivator. They described visiting the prevention clinic to clarify whether they carry a PGV and to gain a better understanding of their risk for PCa.

"[...] I wanted the question of genetic risk to be answered clearly and very quickly." -ID 7, Group 1*.

Group 2 and Group 3 participants also expressed a desire for reassurance about their health status, asking themselves, "Am I really healthy?".

Information needs

Several participants from all groups attended the prevention clinic to receive information and education about PCa, preventive measures, and the interpretation of clinical test results. They also sought a second opinion and the time to ask questions.

"You can ask questions again, and you might notice things yourself that you could do." -ID 12, Group 2.

Benefits for the family

This sub-category was particularly present among participants in Group 1 and Group 3, whereas it appeared less frequently in Group 2. Participants sought to clarify the cancer risk for their offspring, determine whether they might have passed on a genetic predisposition and learn about preventive options for them. Group 3 participants often framed this in terms of genetic test results, but rarely addressed the fact that, due to their own PCa diagnosis, their children already carried an elevated disease risk, even without a PGV.

"[...] I have two children. Are they at risk? [...] Can precautions be taken? Is there anything in the blood that can be detected? When I tell my children about this, they can get tested for it [...]" -ID 4, Group 3.

At the same time, two participants without biological children stated that the topic of heritability played little role for them. Furthermore, one participant mentioned attending the clinic in order to stay healthy for his family, and spend a long life with them.

"They [the family] play a big role, because I would do anything to feel better [...]. So I'll have every test, every operation. The main thing is that it helps me, either to get rid of it [the cancer] or to prolong my life." -ID 12, Group 2.

Another participant also wished to set a good example for his children through his proactive health behavior.

"For me, it's also important, this radiating effect into the family. Especially children observe their parents in life. Grandchildren who come later also observe. And if, as an older person, you set an example that you can do something for your health, that you must do something for your health, even if it requires effort and is uncomfortable and not always pleasant, you should still do it." -ID 4, Group 3.

3.2.2. Additional motivators in men with PGVs or PCa (Groups 2 & 3)

Support others

Three participants reflected on how their participation could benefit not only their families, but also other men at risk for PCa. They

* Quotations have been linguistically smoothed, in particular word slurring, dialects, doublings, and broken words.

emphasised a desire to support scientific progress and help to potentially protect other men from PCa.

"I was so grateful to have been included in this [previous] clinical trial [PROBASE] and that the cancer was discovered that I thought: I'll participate in every study the university hospital offers me if it helps other patients."-ID 3, Group 3.

External Recommendation

Several participants from Groups 2 and 3 reported that recommendations and encouragement from others, including family members, care providers, and invitations from the prevention clinic, influenced their decision to attend the prevention clinic. In some cases, participants were guided primarily by their urologist's recommendation rather than their own initiative. One participant shared that his regular urologist referred him to the prevention clinic for more specialised care and a second opinion due to inexperience with the topic.

"My general urologist [...] didn't really have much experience with that [PGV], how to proceed in such cases. He said he had looked into it and had found this consultation clinic. [...] He said, 'Why don't you go there and talk to them? Maybe they have more experience or know more about it than I do right now.' And that's why I went there."-ID 11, Group 2.

3.2.3. Motivators specific to men with PGVs (Group 2)

Access to structured screening

For most men in Group 2, the accessible, structured clinical PCa examinations provided were the main motivator, as they wanted to take every available screening opportunity given their elevated risk.

"[...] if you go to the urologist here, you won't get out for less than 120, 130 €. [...] I assumed that you would first be examined properly [at the clinic] without having to put your credit card on the table right away, and that you would get a reliable result. [...] And with a reasonable opinion, a reasonable examination, and then probably a few years of peace of mind."-ID 1, Group 2.

In addition to urological examinations, access to mpMRI in particular was mentioned as being limited in standard care. The clinic enabled patients to undergo more intensive PCa screening without additional out-of-pocket costs.

Preventive recommendations

Half of the participants in Group 2 expressed a desire for, and an expectation of, concrete recommendations regarding their PCa screening, particularly with regard to optimal testing intervals.

"[...] my only wish was [...] to receive clear instructions on what needs to be done now."-ID 11, Group 2.

3.3. AIM II: Perceived benefit

This category explores participants' perspectives on helpful elements of the prevention clinic.

3.3.1. Valued elements

Clinical examinations (All groups)

Six participants described the clinical examinations (PSA, mpMRI) as particularly helpful, especially Group 2 participants.

"I always thought the MRI was a good thing, because you just can't look inside the body, right? And it's difficult to check these organs yourself. It's not like with a broken finger, you can feel that [...]"-ID 12, Group 2.

Genetic testing (Groups 1 and 2)

Other participants described genetic testing as the most important component and foundation for understanding their risk.

"Genetic testing is obviously the most important thing, because that's what sets the ball rolling in the first place."-ID 8, Group 2.

In contrast, one participant viewed genetic testing as less relevant for himself, primarily because he did not have children.

Overall concept (Groups 2 and 3)

At the same time, five participants from Groups 2 and 3 stated that no

specific element of the clinic was perceived as more important to them and underlined the perceived value of the overall concept.

Counselling (Group 3)

A subgroup of participants from Group 3 highlighted the support and counselling as important.

"And I also think the follow-up support is very good. I think that's crucial too."-ID 4, Group 3.

3.3.2. Knowledge gain and Empowerment

All participants stated that the communication of information was clear and understandable. The ability to obtain personalised, actionable information, as well as to have sufficient time to ask questions, and receive clear results, was frequently mentioned. Eleven participants explicitly stated that the clinic met their personal reasons for participating. In addition to gaining knowledge about inheritance patterns, personal risk, and monitoring strategies, participants expressed relief in now having a reliable point of contact for future concerns.

"[...] I was totally happy and felt relieved. That I now have another place where I can get a little more information about my problem, which may be smoldering inside me."-ID 13, Group 1.

Participants also noted that they gained new, unexpected information for themselves.

[Asked about personal insights] The probability of developing cancer is not as high as I had imagined [...] before I had a 100% risk in mind, and now I'm very, very happy that it's actually not even half that."-ID 8, Group 2.

3.4. AIM III: Optimisation suggestions

3.4.1. Logistics and access

Most of the recommendations from participants from all three groups concerned organisational aspects. For example, improving availability by telephone and providing a clear timeframe for the waiting time for genetic test results to avoid uncertainty were suggested. Participants also recommended providing help with finding your way around the large hospital.

"[Asked about recommendations] A checklist or info sheet [...] for the MRI building. When someone is sent there, with a small sketch: what is where, how to get there."-ID 1, Group 2.

Participants valued the provided option to receive clinical results by telephone, particularly due to travel distances. Further suggestions included the provision of psychological support, providing written genetic results in English for family members, more extensive follow-up genetic counselling to discuss the results of the genetic test, and information on what to expect in the event of a future PCa diagnosis, to help prepare mentally for this possibility.

3.4.2. Follow-up outreach

Three participants of Groups 2 and 3 wished for an active reminder system for their next PCa screening appointments (PSA test, mpMRI) to avoid missing follow-up visits.

"[Asked about recommendations] Where the clinic actively reaches out to me at some point like, 'Hey, you need to come by again,' or 'We need to take some blood again,' [...] I would really like that. [...] Because then I wouldn't have to take care of it myself. Or if I forget, at least someone else will remember."-ID 10, Group 2.

4. Discussion and conclusion

This qualitative interview study assessed participants' experiences alongside Germany's first prevention clinic for familial and genetic PCa predisposition. Our findings indicate information needs regarding PCa risk status and suggest acceptability of the investigated prevention clinic, reinforcing calls for coordinated PCa early detection pathways [6, 18,44]. In a next step, targeted outreach could use the identified motivators to reach men at elevated PCa risk more effectively and to increase

awareness for risk-adapted early detection.

Participants' decisions to attend the prevention clinic were based on multifactorial reasons, with most reporting more than one motivator. The key motivators for participation identified in the interviewed subgroup were "clarifying risk and PGV status", "perceived benefit for family", "access to structured screening" and "external recommendation". These findings are consistent with prior research among men with PGVs in *BRCA* genes, men at risk of PGVs, and men with PCa undergoing genetic testing [14,18,24,45]. Our study extends the previous findings by demonstrating group-specific patterns of PCa and PGV status. Participants with a family history primarily sought clarity regarding both their own risk status, and potential implications for their family. Participants with a known PGV were mainly motivated by access to structured and cost-free screening within the clinic, external referral and the receipt of clear screening recommendations. These motivators also highlight the current care gap within PCa early detection: Although men with PGVs are aware of their elevated cancer risk, guidelines for risk management are inconsistent, and risk-adapted PCa screening is rarely offered within structured care settings. In Germany, PSA testing requires out-of-pocket payment when performed without a clinical indication. Genetic testing and MRI for men with familial cancer risk are usually covered by statutory health insurance when guideline-based criteria are met. However, access often requires referral to specialised centers and case-by-case insurance approval.

Overall, the findings suggest that both self-oriented and altruistic motives played a central role in motivating men at increased PCa risk to participate in early detection. Self-oriented motives involved clarifying personal risk and seeking information, and altruistic motives reflected contributing to research and supporting family members. The identified motivators also overlap with the key determinants "risk perception" and "outcome expectancies" of intention formation within the HAPA. This supports the relevance of these motivators to men's participation in PCa early detection [22].

Regarding perceived helpful elements, participants valued the different components of the clinic (clinical examinations, counselling, genetic testing, screening recommendations) to different extents. In line with their key motivators, men with a PGV considered clinical examinations as particularly important. Participants described a strong need for actionable information to reduce uncertainty regarding their PCa early detection. Therefore, participants emphasised the advantages of the expert setting, which allowed time for questions, provided clear guidance, and offered a reliable point of contact. The reported knowledge gain also contributed to feelings of empowerment, personal control, and relief. These motivators are in line with the factors self-efficacy, action plans and action control described in the volition phase of the HAPA. Long-term engagement in PCa early detection may therefore be supported by strengthened self-efficacy and support of participants. The results are also consistent with previous literature that described the positive impact of genetic counselling on anxiety and personal control, and the importance of clearly communicating genetic results [46–48].

In addition to information needs, the interviews revealed potential knowledge gaps among both patients and physicians regarding hereditary PCa, in line with previous studies [16,49–51]. Participants with PCa tended to view their children's risk mainly in terms of passing on a PGV, but showed less awareness that a family history of PCa itself increases risk. The varying perceptions of the relevance of clinic components further suggest that the interconnected risk assessment process is not intuitive for all participants. This highlights the need for clear communication regarding hereditary risk mechanisms and the rationale behind risk assessment. Furthermore, gaps in experience of patients' physicians with genetic cancer risk were mentioned, supporting the need for improved access to information materials and targeted professional training.

Summing up, our findings highlight the importance and acceptance of risk-adapted early detection for men with a familial or genetic PCa risk, as demonstrated by the example of the prevention clinic at the UKD.

Nearly 85% of the interviewed subgroup stated that the prevention clinic met their reasons for participation.

4.1. Practice implications

The acceptance of the prevention clinic and the identified information needs of participants support the implementation of targeted early detection programmes for men at elevated PCa risk [6,44]. Communication training for genetic counsellors and urologists should focus on clear and actionable recommendations regarding the next steps for patients instead of focusing solely on risk disclosure. The identified information gaps of participants, even after genetic counselling, indicate that hereditary risk communication should be supported by patient-adapted written material. The integration of family-centred counselling may also be beneficial for guidance on risk communication within the family and cascade testing strategies.

To encourage participation among men at elevated PCa risk, recruitment should emphasise access to structured screening, clarity regarding personal risk, and implications for family members. Health care providers emerged as gatekeepers and motivators for participation. Raising awareness of male genetic cancer risk, particularly in primary care, is therefore crucial. Identification of high-risk individuals may be improved by integrating routine family history screening, e.g. through digital tools usable across a spectrum of providers [52]. The reported provider-related barriers further underline the importance of targeted training on PCa risk factors. Hereditary risk in men remains under-recognized and often seen as primarily relevant for female relatives [12,53].

Participants proposed concrete improvements for PCa early detection. Active follow-up screening reminders may support long-term adherence to screening recommendations. Additional considerations include clinic navigation support, transparent timelines for results, availability by phone and email, psychological follow-up support, and multilingual materials.

Future research should examine the acceptability and feasibility of PCa early detection offers in larger scale cohorts. The implementation of strategies that enhance patient-centredness and reduce identified barriers should also be prioritised.

4.2. Limitations

Limitations of this study include a relatively homogenous sample of White men from Germany with comparatively high educational backgrounds. Self-selection bias of participants within this study is likely, as participants were already motivated for early detection. Familiarity with PCa early detection, high health literacy, and education may therefore have influenced the willingness to engage in a PCa prevention clinic. Men with a family history and without PCa or PGV were underrepresented in this study. Moreover, only one participant was found to carry a newly identified PGV and one participant was diagnosed with PCa. For most participants, test results were reassuring and subgroup-specific perspectives, especially among men with a newly identified PGV, may not be fully captured.

The results should also be interpreted within the context of the German healthcare system and its specific reimbursement and access structures. Access to cost-free structures emerged as a key motivator and may not translate to other healthcare settings.

Finally, the study reflects experiences during the early implementation phase of the clinic. Perceptions may shift as such services become more established. Future research should explore motivators, barriers and adaptation needs among men at elevated PCa risk who choose not to participate in PCa early detection. Furthermore, studies investigating the feasibility of risk-adapted PCa early detection in a bigger sample and a more diverse population are warranted.

5. Conclusion

This study provides initial insights into the experiences of participants attending a risk-adapted prevention clinic for men at familial or genetic PCa risk in Germany. Participation was based on multifactorial motivators, encompassing both self-protective and altruistic motives. In addition, participants suggested the need for comprehensive approaches, with clear and personalised information. Active outreach and structured follow-up were perceived as important for long-term engagement. Access to structured, cost-free PCa screening was particularly valued by men with a PGV, underscoring the importance of integrating risk-adapted PCa screening offers into routine care. These results can inform future outreach and early detection strategies aimed at earlier identification and referral of high-risk men.

CRediT authorship contribution statement

Maike K Klett: Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Methodology, Investigation, Formal analysis, Data curation. **Ilayda Balkan:** Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Investigation, Formal analysis, Data curation. **Jale Lakes:** Writing – review & editing, Resources, Methodology. **Peter Albers:** Writing – review & editing, Supervision, Resources, Methodology, Funding acquisition, Conceptualization. **Kati Hiltrop:** Writing – review & editing, Supervision, Methodology. **Jannika Rother:** Writing – review & editing, Supervision, Methodology. **Matthias Boschheidgen:** Writing – review & editing, Resources. **Gerald Antoch:** Writing – review & editing, Resources. **Silke Redler:** Writing – review & editing, Resources. **Dagmar Wieczorek:** Writing – review & editing, Resources. **Tanja Fehm:** Writing – review & editing, Resources. **Bernadette Anna Sophia Jaeger:** Writing – review & editing, Resources. **Ulrike Dinger:** Writing – review & editing, Supervision, Resources. **André Karger:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

Ethics approval

Ethics approval from the Medical Faculty of the Heinrich-Heine-University Düsseldorf was obtained (2023–2551). All participants gave written informed consent.

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Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used DeepL Write and ChatGPT in order to strengthen the language style and comprehensibility in English. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

Declaration of Competing Interest

The authors declare that they have no competing interests.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pec.2026.109593.

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