

What makes a trial appealing for a patient?

Alastair Lamb

Cancer Research UK Clinician Scientist Fellow
& Honorary Consultant Urologist, Oxford

Brussels

bmuc.be/bmuc2024



11th Belgian Multidisciplinary
Meeting on Urological Cancers

 @lambalastair

Our Events

Everyone is welcome to come. They are informative and fun.

We run regular awareness events, informative events and socials - where we get together in an easy environment to chat. Do come along.



Coming up

23 May 2022 - 7:00pm Clinical Research in Oxford and beyond

Richard Bryant and Alastair Lamb will provide an update on the TRANSLATE Tria

Venue: Oxford Golf Club and Online

[See all events](#)

Sponsors & Friends



Please click on each person to read their stories.



Caroline Prance



Charlotte Minett



Dafydd Charles



Dave and Jean Hawes



David Beesley



Steve Tuck

Oxfordshire Prostate Cancer Support Group has been providing support to those affected by prostate cancer since 2011. We provide friendship and support to patients, their partners and family.

We've traditionally used our initials, OPCS as a short name, but are now in the process of rebranding to use OxMen, but are and will continue to be, the Oxfordshire Prostate Cancer Support Group.

We offer the opportunity to connect with others that have been in the same situation, to listen and share their own relevant experience of treatment and living with, and beyond, prostate cancer.

If you or someone close to you has been affected by prostate cancer, we can offer:

- One-to-one meetings with a member who has relevant experience;
- Group meetings for everyone, both in-person and on-line;
- Separate private meetings for patients and partners to share worries and successes;
- Social events, such as river cruises and skittles;
- A newsletter with updates about upcoming events (hosted by OxMen and others);
- Talks from experts, including representatives of:
 - The Urology Department at Oxford University Hospital Trust,
 - Prostate Cancer UK,
 - Maggie's,
 - Prostate Cancer Research,
 - Clinical Trials and Studies.

Our group meetings are safe spaces where we regularly discuss the physical and emotional impact of prostate cancer and treatment and share our personal experiences. We also offer one-to-one support and the opportunity to speak to people with experience of different treatments for those trying to make a decision; we do not offer medical advice, but will try to match you up with someone who can share their experience of a treatment you are interested in. This is open to everyone affected by prostate cancer, not just patients.

Email support@oxmen.org, or call 01865 595109, if you need support.

Partners can also contact us for dedicated support by emailing partners@oxmen.org directly.

Get Checked

If you are over 50 (younger for those with relevant family history and black men) you should talk to your GP about a prostate health check even if you have no symptoms. Catching prostate cancer early gives you a far better chance of beating it.

Symptoms and getting checked





Some questions

- What do you think?
- Names:
 - Patient-initiated follow up
 - Patient-led follow up
 - Patient-orientated follow up
 - Patient-centred follow up
 - Other ideas?
- After prostatectomy, radiotherapy, medical oncology treatment – does that sounds okay?
- Online portal registration – mandatory or not?
- Anything else?



1 Stratified Follow-Up
Alastair Lamb, Charlotte Murray & the Prostate Cancer Team

2

3

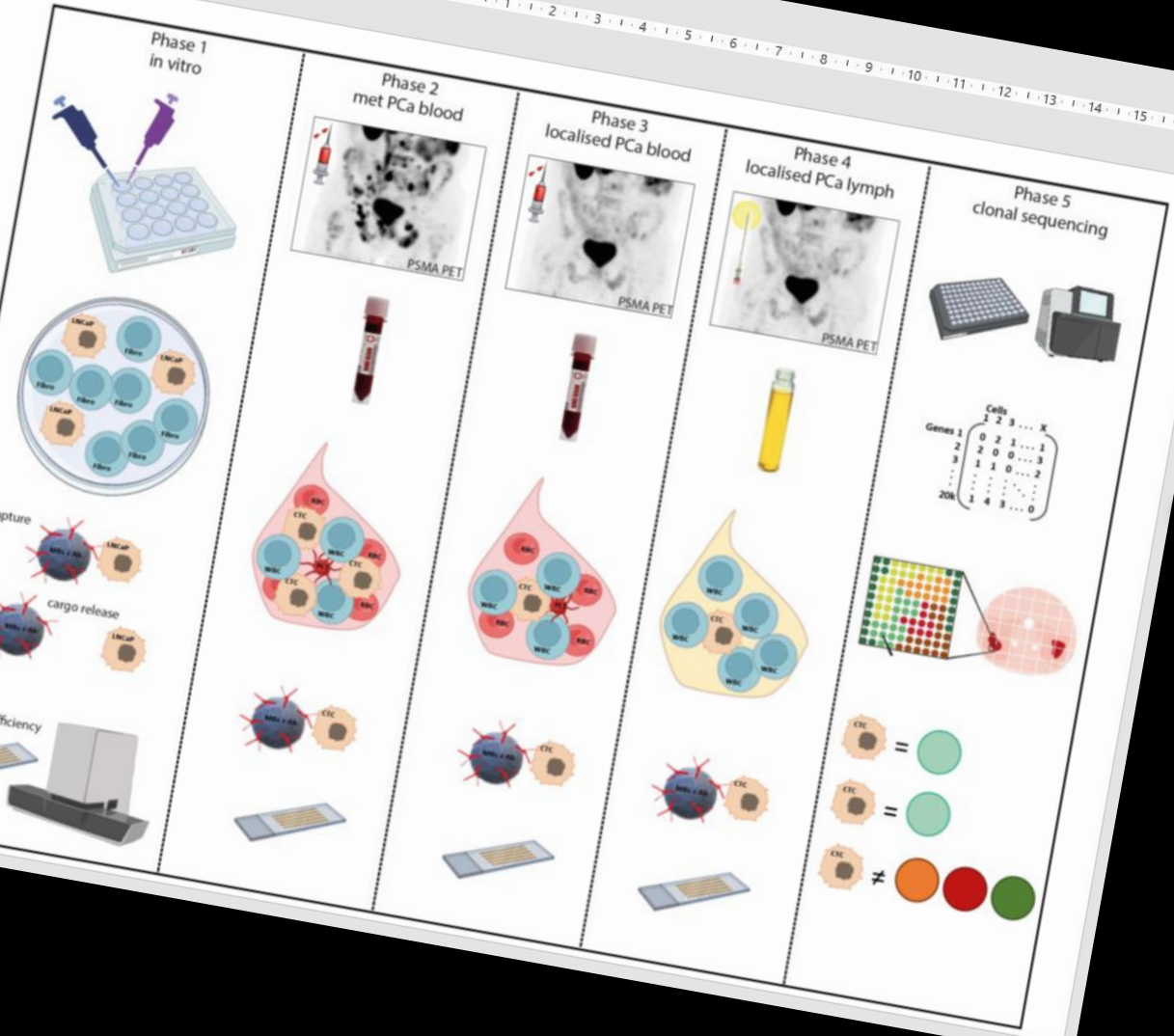
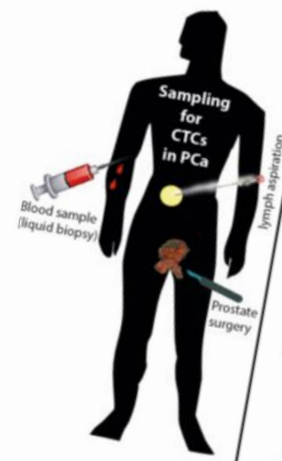
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5 Some questions

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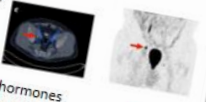
PROSTATE CANCER UK
Leading opportunities
Research Innovation Awards



OMEN-PET

Occult metastases & lymph Nodes detected by psma PET
(and not detected by conventional imaging)

- RCT
2 arms:
1. Radical Prostatectomy or Radiotherapy & hormones
 2. Systemic therapy with hormones & chemotherapy



QUANTUM
Department of Surgical Sciences

Will men with prostate cancer, or their relatives/partners etc., be involved in the design, planning or management of this research?

Yes

Please elaborate on their role (in no more than 500 words).

We have a close relationship with the Oxford Prostate Cancer Support Group (OPCSG; <https://www.opcsg.org/homepage.>), led by Mr Steve Tuck. We can provide evidence of collaboration from our recently NIHR-funded randomised controlled trial investigating techniques in prostate biopsy (the TRANSLATE Trial)(61) and our application to Cancer Research UK(62) for funding to support the QUANTUM Biobank with a prospective sample collection, also supported by OPCS. We regularly present our research programme to OPCS at one of their monthly Monday evening meetings at which we are regular speakers, and likewise present our findings to update them on progress. Although we do not plan to include a PPI member as a co-applicant on this award, we believe that we already have the required PPI support for QUANTUM, this being the medium through which patients who contribute samples to this study will be recruited. Steve Tuck is a member of our Tissue Access Committee for QUANTUM and has kindly reviewed and provided feedback on the lay components of this PCUK Research Innovation Award application.

Pre-submission

**PROSTATE
CANCER UK**

Fourth floor
The Counting House
53 Tooley Street
London SE1 2QN

Telephone 020 3310 7000
Fax 020 3310 7107
info@prostatecanceruk.org
prostatecanceruk.org



← Tweet



Alastair Lamb
@LambAlastair

...

Really enjoyed our evening with [#OPCSG](#) Oxford Prostate Cancer Support Group [@oxford_golfclub](#) (1st time back in person!) updating on [#TRANSLATE_Trial](#) & [@LabBryant](#)'s plans for future [#TopNotchScience](#) in [#ProstateCancer](#).

Great crowd. Great questns.

Thanks [@SteveTuck](#) for having us



5:38 PM · Sep 15, 2021

View Tweet analytics

Promote

3 Retweets 16 Likes



Alastair Lamb @LambAlastair · May 28, 2022

...

[@mercaderclaudia](#) talks to Oxford Prostate Cancer Support Group [#OPCSG](#) about "Why come from Barca to Oxford to do a fellowship?"

5 lessons learned:

- not only 1 way to do things
- ask why
- involve ur pts
- learn from ur results
- England is more than just London!

[#Oxford_Urology](#)



Steve Tuck and 9 others

← Tweet



Alastair Lamb
@LambAlastair

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#Oxford_Urology



CEL
@CELovegrove

Well, this is encouraging! #OPCSG #Waterworks #PCa #prostatecancer #OxfordUrology @OUHospitals @NDSurgicalSci opcs.org



5:05 PM · Jul 7, 2019

PATIENT & PUBLIC INVOLVEMENT

Please describe how patient and the public have been involved in developing this proposal

Patients and the public have been actively involved in the conception and development of this proposal. A preliminary meeting was organised by the Oxford Prostate Cancer Support Group on 14/10/19 where Alastair Lamb (Co-Lead Investigator) introduced the trial concept and asked for feedback. The meeting was attended by 52 people including previous prostate cancer patients, their partners and friends. They were asked to consider four questions:

1. What most concerns / concerned you about having a prostate biopsy?
2. Would men accept randomisation between the two forms of biopsy (given that the current standard of care is transrectal biopsy)?
3. What most embarrassed you/would most embarrass you about having a biopsy?
4. How best to record outcomes after a biopsy?

The trial team discussed the answers to these questions after this first meeting to inform the content of the first stage application. There was general agreement that there is lack of evidence with regards to the approach to diagnostic prostate biopsy, and that patients and their families agreed that the TRANSLATE Trial is very worthwhile and likely to improve patient management and should proceed. As a result of this meeting first meeting, Mr Steve Tuck (OPCSG chair and previous prostate cancer patient) volunteered to be a co-applicant on this application, and to act as patient advocate for the trial. The OPCSOG agreed to support the TRANSLATE trial, and to perform an anonymous survey prior to submission of stage 2 of the application, and to publicise the trial and its findings within their, and other, related groups, and on their website and in their newsletter.

After several meetings of the trial management group with Mr Steve Tuck, a confidential survey was undertaken between 26th March to 30th April 2020 by OPCSOG amongst its members, and amongst other patient members of NCRI Prostate, and Thames Water – the latter being important to include a sample of men who had not already undergone a prostate biopsy. Eight questions were included, covering the above items and anonymous demographic data. There were 72 respondents, 60% of whom had not previously undergone prostate biopsy. Of these 58 (80%) were 'very likely' or 'likely' to accept randomisation, and 70% would be 'very willing' or 'willing' to be randomised on the day of the procedure. The vast majority rated 'diagnosis of cancer' as the primary concern in undergoing a biopsy, with 'avoiding infection (sepsis)' a close second concern. The need to avoid repeat biopsy was 'very important' or 'important' for 80% of men, and it was interesting to note that surprisingly few men (15%) were concerned about loss of erectile function. The survey also highlighted the concern to avoid pain/discomfort, and to maintain personal dignity.

The trial management group believe that the results of this survey conducted by OPCSOG underline the importance of investigating detection of clinically significant prostate cancer as the primary outcome, with infection rates and patient perception of the biopsy as important secondary outcomes. In light of the feedback regarding perception of discomfort and personal dignity, we have amended the patient reported outcome measures (PROMs) to include assessment immediately after the procedure, as well as at 7 days, in order to minimise the possibility of 'recall bias' or 'context bias' in the event of a pleasing outcome from the biopsy (i.e. avoidance of a prostate cancer diagnosis).

Please describe the ways in which patients and the public will be actively involved in the proposed research, including any training and support provided

Patients and the public will continue to be actively involved throughout the trial. Mr Steve Tuck, as a co-applicant, will attend regular trial management group meetings. We will continue to update the Oxfordshire Prostate Cancer Support Group (OPCSOG) and the National Cancer Research Institute (NCRI) patient advocates about the progress of the trial.

If funding is awarded, members of the OPCSOG will be involved in the design and final approval of the patient information sheet, the family information sheet and the consent form for the TRANSLATE trial. Their involvement is vital to help make the language and information content of these documents

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understandable to patients and families at a period of great stress, and to make them relevant to recruitment centres across the UK.

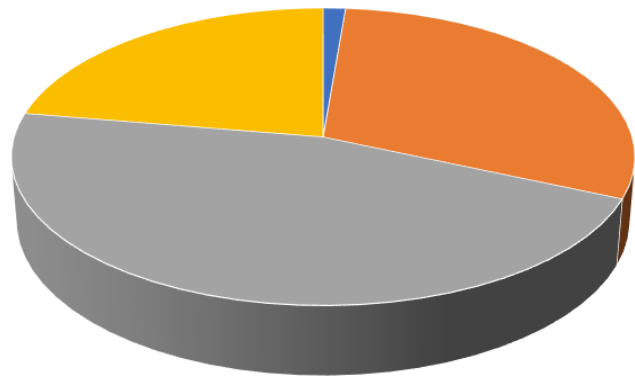
We outline below the ways in which our PPI colleagues will continue to be involved through the trial:

1. Research design: Mr Steve Tuck will continue to be involved in regular Trial Management Group meetings to finalise the trial design.
2. Research Management: Individuals who agree to contribute to the management of the project will meet the Clinical Trials Unit (CTU) individually, to gain understanding of their previous involvement in clinical trials (if any). Appropriate training will be offered and participation will be tailored appropriately. The induction pack for PPI contributors on Trial Oversight Committees is invaluable, preliminary reading.
3. Participant information resources development: A short video for potential participants describing the trial will be available on the CTU website. The lead applicants will explain the background and rationale for the trial, and what participation would entail. Patient/carer feedback for this will be vital, for which we will engage OPCSOG. Furthermore, a number of patients have expressed a desire for involvement in the writing of the patient information sheet, and relevant details for inclusion on the trial website. In addition, with appropriate permission, short videos will be made available of trial participants, providing their real life experience of inclusion (e.g. the questions asked, assessments undertaken, etc).
4. Contribution to research reporting: As a NIHR funded project, the standard monograph will be produced, however we will be working with our PPI collaborators to ensure any plain English parts of the monograph are phrased appropriately to ensure that the findings can be interpreted correctly by all audiences, and we would hope to produce an infographic if possible, to explain the findings.
5. Dissemination of research findings: With our patient co-applicant, and PPI groups mentioned above, communication for patients/carers and the public will be developed. Newsletters, Facebook, Twitter etc. will be used to ensure the results of TRANSLATE are communicated to the wider community once they are available. In addition, the TRANSLATE team will follow the Public Involvement Impact Assessment Framework to maximise PPI in the trial.

In rare cases where proposals do NOT involve patients and the public, clear justification must be provided

N/A

Q3. How willing would you be to be allocated at random to TRUS or LAMP biopsy ON THE DAY of the procedure?



■ Very unwilling ■ Unwilling ■ Willing ■ Very willing

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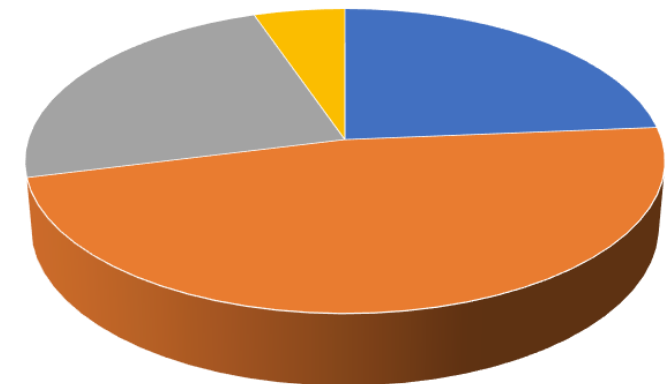
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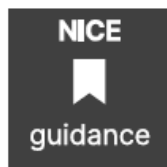
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4. Contribution to research reporting: As a NIHR funded project, the standard monograph will be

Q5. How important is it to avoid the need for a repeat biopsy?



■ Extremely Important ■ Very Important ■ Somewhat important ■ Not at all important



Transperineal biopsy for diagnosing prostate cancer

Diagnostics guidance
Published: 1 June 2023

www.nice.org.uk/guidance/dg54

1 Recommendations

1.1 Local anaesthetic transperineal (LATP) prostate biopsy using the freehand needle positioning device PrecisionPoint is recommended as an option for diagnosing prostate cancer.

1.2 Although there is considerably less evidence and therefore greater uncertainty of clinical benefit for them, the following freehand needle positioning devices are expected to have similar cancer detection rates and adverse events to those of PrecisionPoint:

- EZU-PA3U device
- Trinity Perine Grid
- UA1232 puncture attachment.

There are technical differences between them, but they all work in a similar way using the same biopsy technique. So, these devices are recommended as options for diagnosing prostate cancer.

1.3 Centres are encouraged to take part in research and data collection, including the randomised controlled trial of transrectal biopsy compared with LATP biopsy (the TRANSLATE trial; see [section 3.8](#)) to help refine clinical practice.

1.4 There is not enough evidence to recommend double freehand LATP prostate biopsy using the CamPROBE device. Further research is recommended to understand its clinical effectiveness.

Why the committee made these recommendations

Standard prostate biopsy uses local anaesthetic transrectal ultrasound (LA-TRUS). This involves taking samples of prostate tissue by inserting a biopsy needle through the rectal wall via the anus. An alternative is LATP prostate biopsy, which involves inserting the needle through the perineum, the skin area between the anus and the scrotum.

Techniques for LATP biopsy vary. It can be done using a freehand needle positioning

Clinical experts explained that there is a move towards using LAMP nationally and that some centres no longer do TRUS prostate biopsies.

Participation in the ongoing TRANSLATE RCT is encouraged to generate further evidence to help refine clinical practice

3.8 The ongoing [TRANSLATE RCT](#) will provide further comparative evidence on LA-TRUS biopsy and LAMP biopsy using a freehand needle positioning device. The trial aims to recruit 1,042 people with a prostate over 15 months from 9 NHS hospitals in the UK. The protocol says that an average of around 12 systematic biopsy cores will be taken, depending on prostate size, with an additional 4 target biopsy cores for each significant lesion seen on prebiopsy MRI. The primary outcome is detection rates of clinically significant prostate cancer. Secondary outcomes include rates of infection, health-related quality of life, patient-reported tolerability of the procedure, patient-reported biopsy-related complications, number of subsequent prostate biopsy procedures, cost effectiveness, and histological parameters. The trial will last for 31 months and is expected to end in October 2023. **The committee concluded that centres should be encouraged to participate in research and data collection, including the TRANSLATE RCT, to generate more evidence to help understand the effects of differences between the LAMP and LA-TRUS biopsy approaches and refine clinical practice.**

Cost effectiveness

The committee prefers the new assumptions used in the EAG's revised analysis

3.9 The committee considered the original and revised base-case analyses and noted that in the revised analysis, the key differences with the largest effect on the incremental cost-effectiveness ratios (ICERs) were that:

- studies that used spinal anaesthesia were excluded

6 Diagnostics advisory committee members and NICE project team

Committee members

This topic was considered by the [diagnostics advisory committee](#), which is a standing advisory committee of NICE.

Committee members are asked to declare any interests in the tests to be assessed. If it is considered there is a conflict of interest, the member is excluded from participating further in that assessment.

The [minutes of each committee meeting](#), which include the names of the members who attended and their declarations of interests, are posted on the NICE website.

Additional specialist committee members took part in the discussions for this topic:

Specialist committee members

Hashim Ahmed
Professor of urology, Imperial College Healthcare NHS Trust

Tristan Barrett
Consultant radiologist, Addenbrooke's Hospital, Cambridge

Sanjeev Madaan
Consultant urological surgeon and lead cancer clinician, Darent Valley Hospital, Dartford

Jon Oxley
Consultant in cellular pathology, North Bristol NHS Trust

Michele Pietrasik
Prostate cancer clinical nurse specialist, Royal Surrey County Hospital NHS Foundation Trust

Graeme Spencer
Lay specialist

Santhanam Sundar
Consultant oncologist, Nottingham University Hospitals NHS Trust

David Wakefield
Lay specialist

Clinical expert

Hide Yamamoto
Consultant urologist, Maidstone and Tunbridge Wells NHS Trust

NICE project team

Each diagnostics assessment is assigned to a team consisting of a technical analyst (who acts as the topic lead), a technical adviser and a project manager.

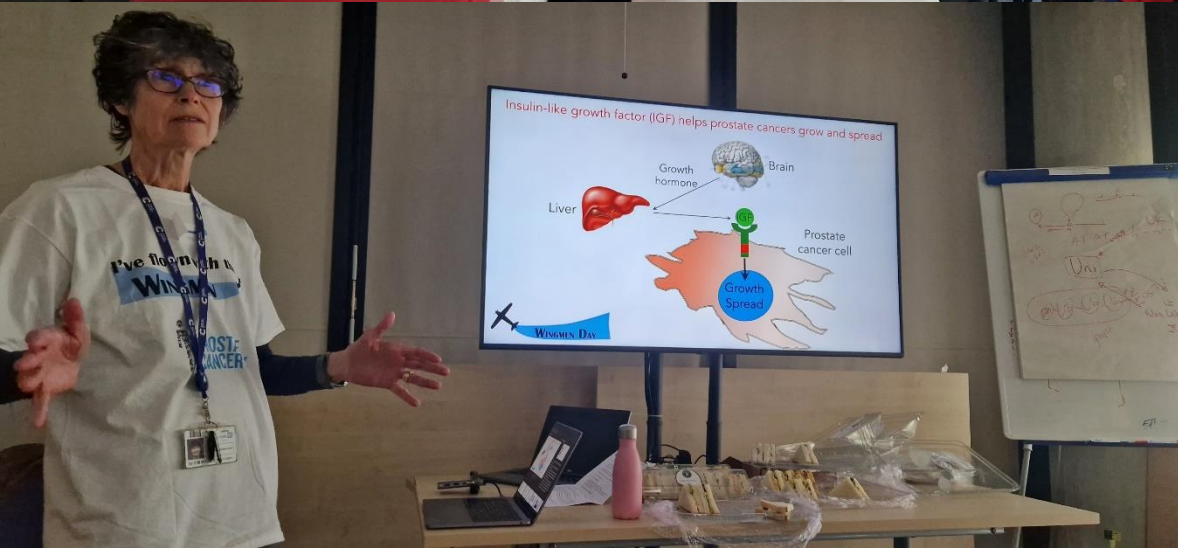
Simon Webster
Topic lead

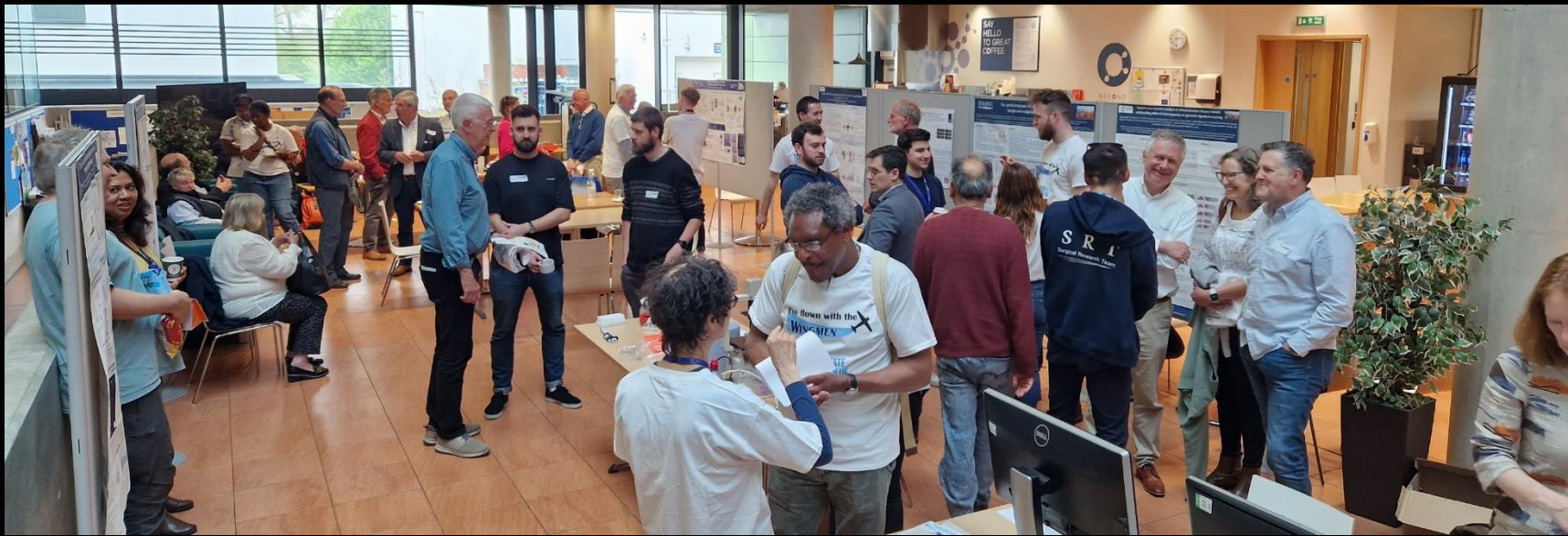
Frances Nixon
Technical adviser

Donna Barnes
Project manager (February 2021 to April 2022)

Toni Gasse
Project manager (May 2022 to June 2023)

ISBN: 978-1-4731-5199-4





Clinical Trial Participation Survey

This survey aims to understand what factors make clinical trials appealing to potential participants.

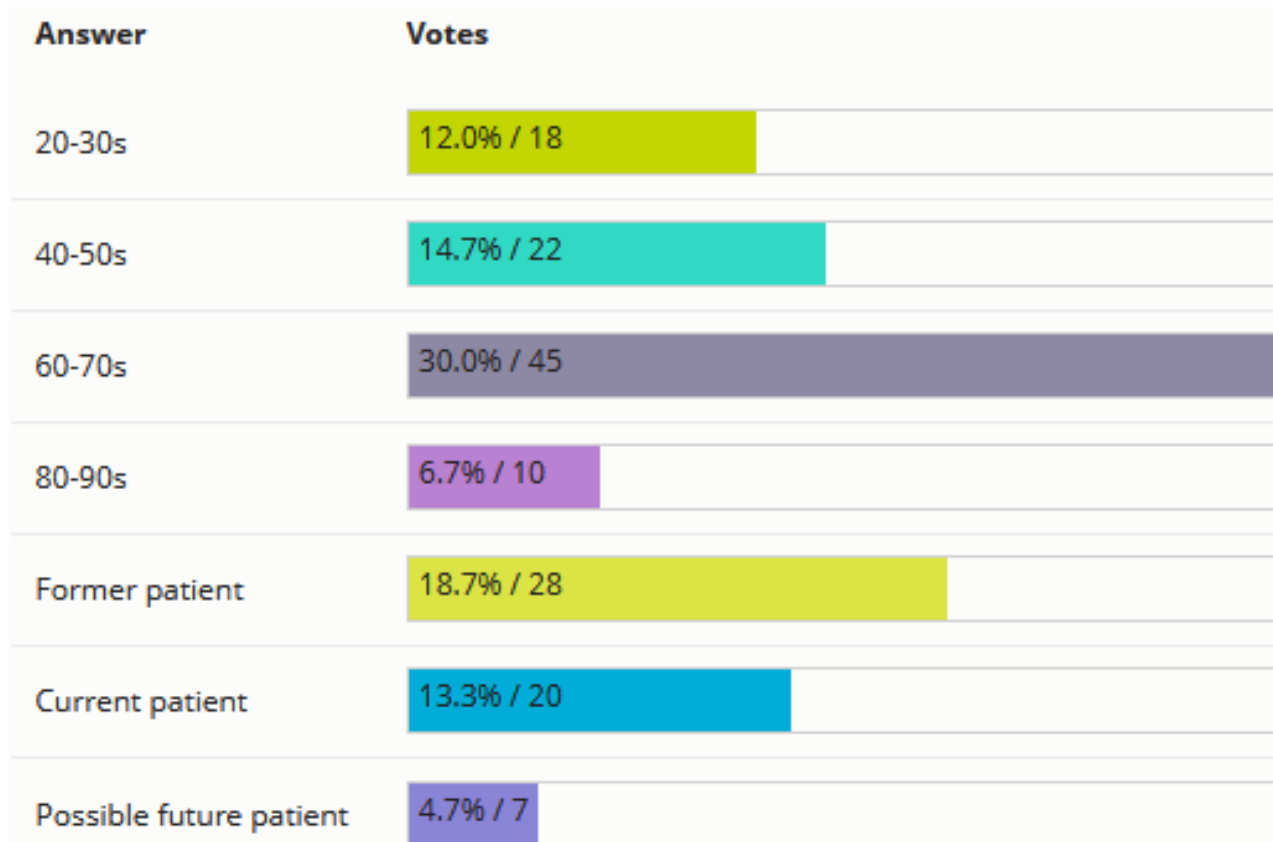


START

opinion stage - create your own survey



Please tell us a little about you:



Views ?

182

Started ?

71% (130)

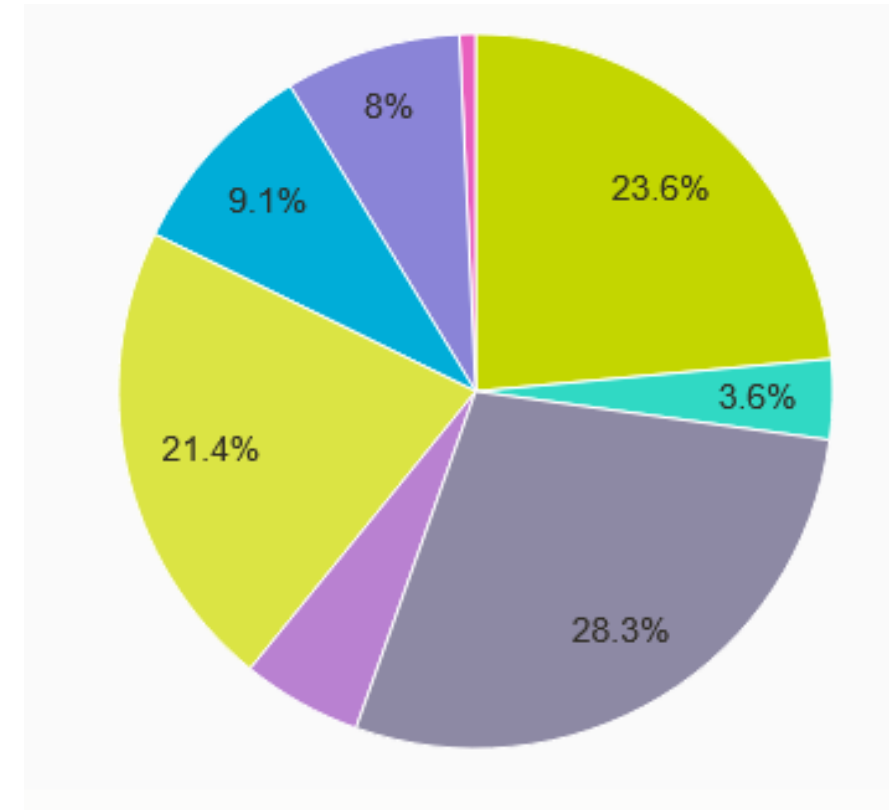
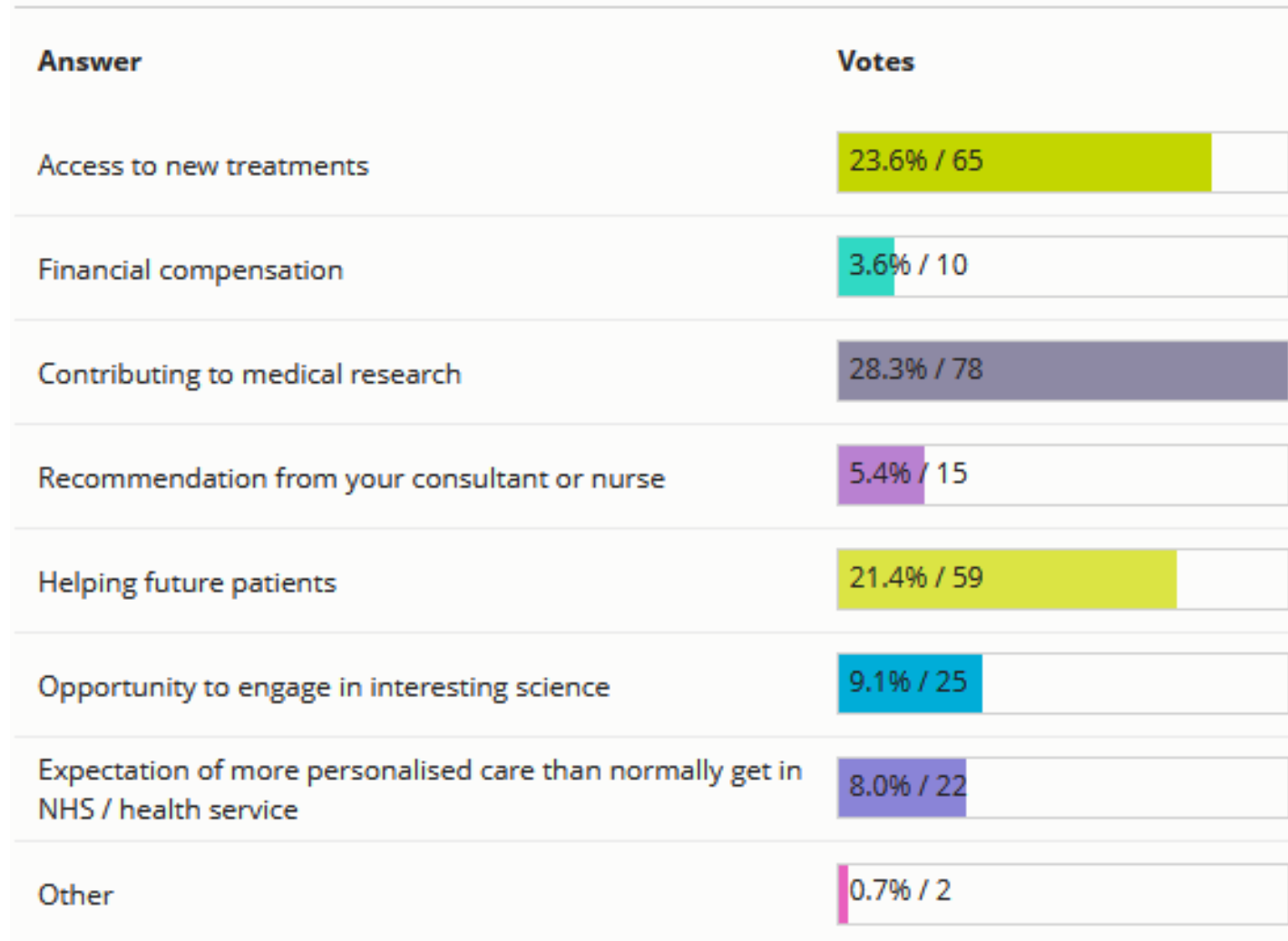
Completed ?

77% (100)

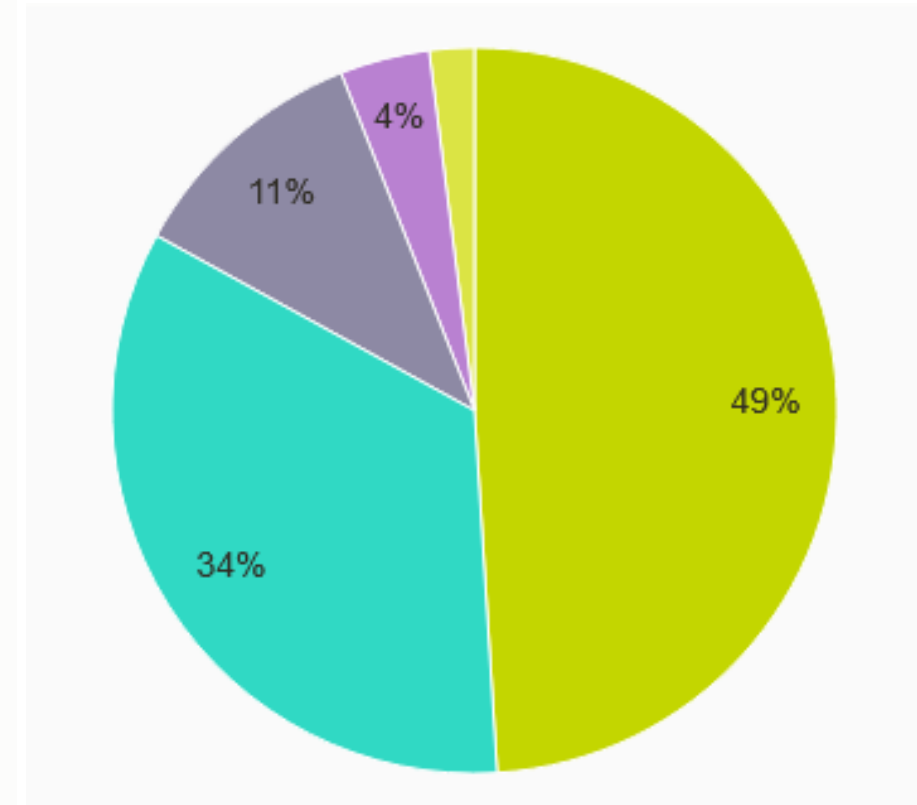
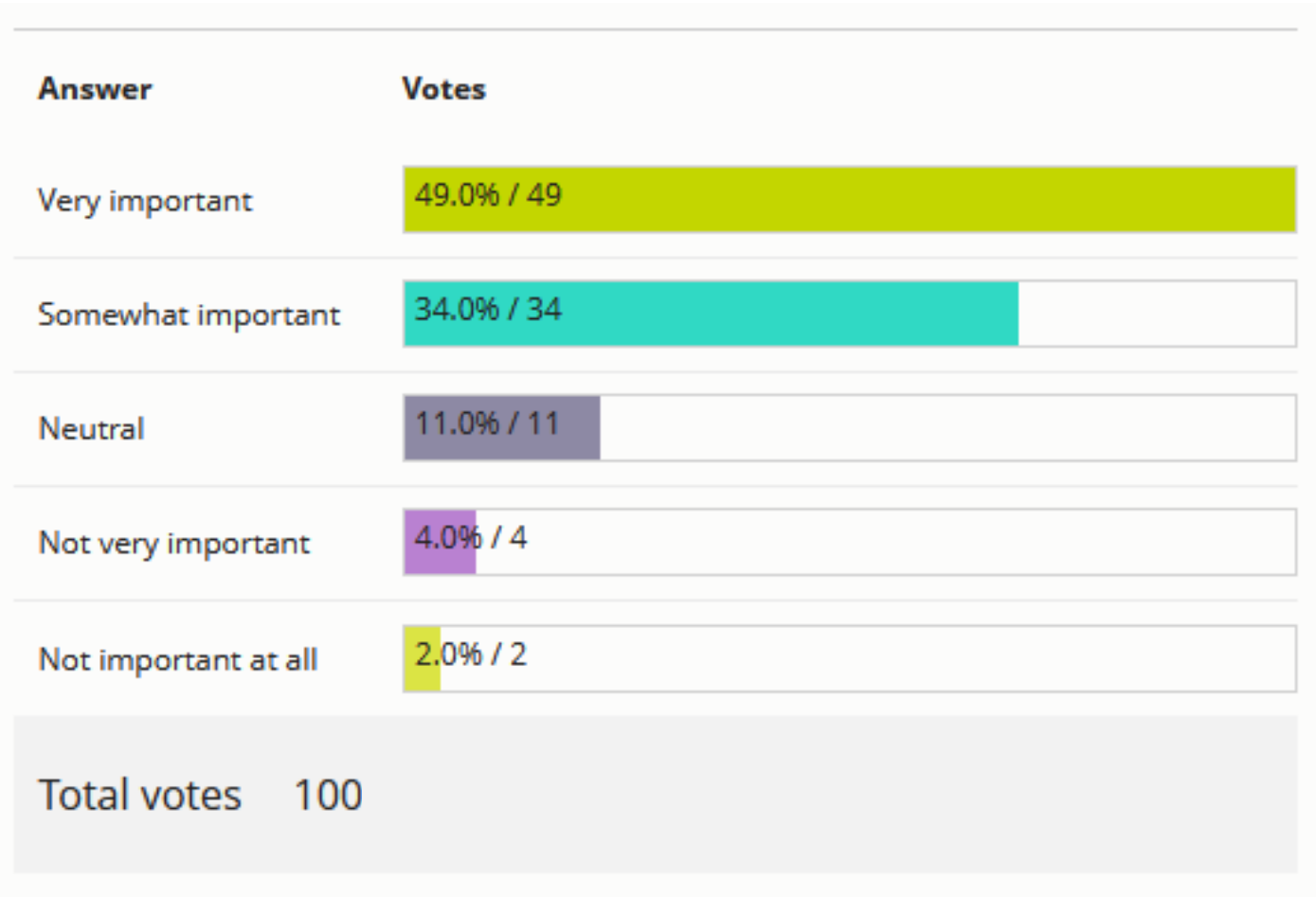
Average Time ?

4:44

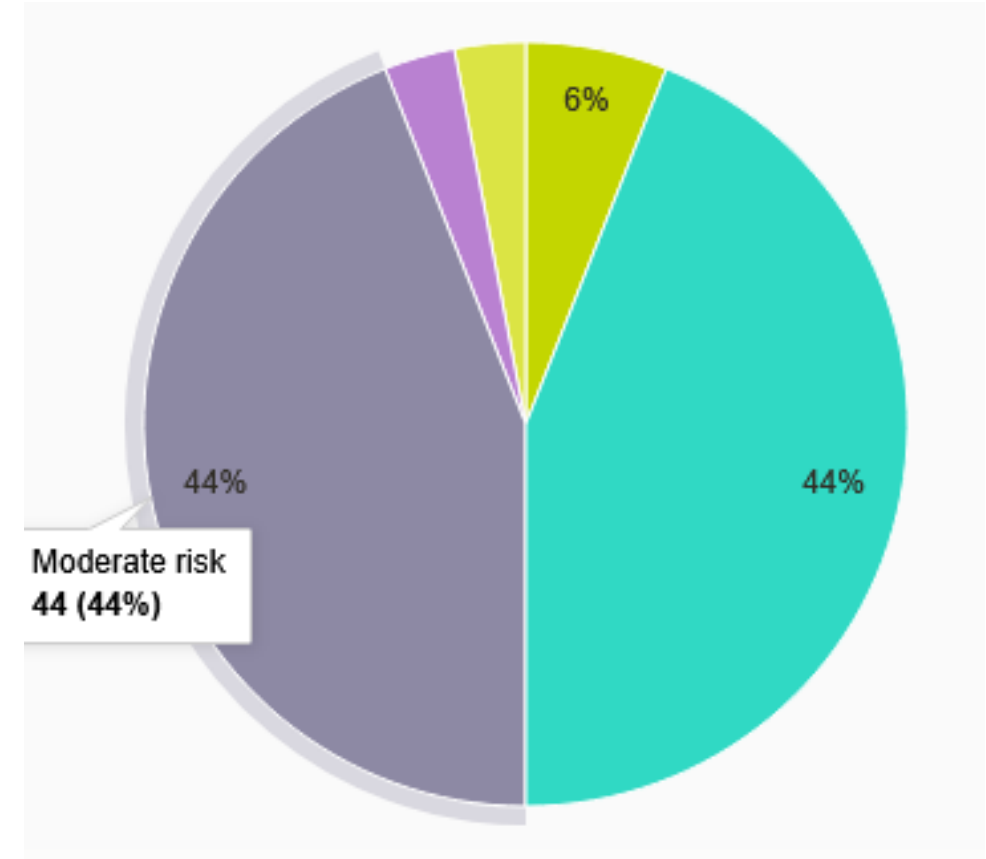
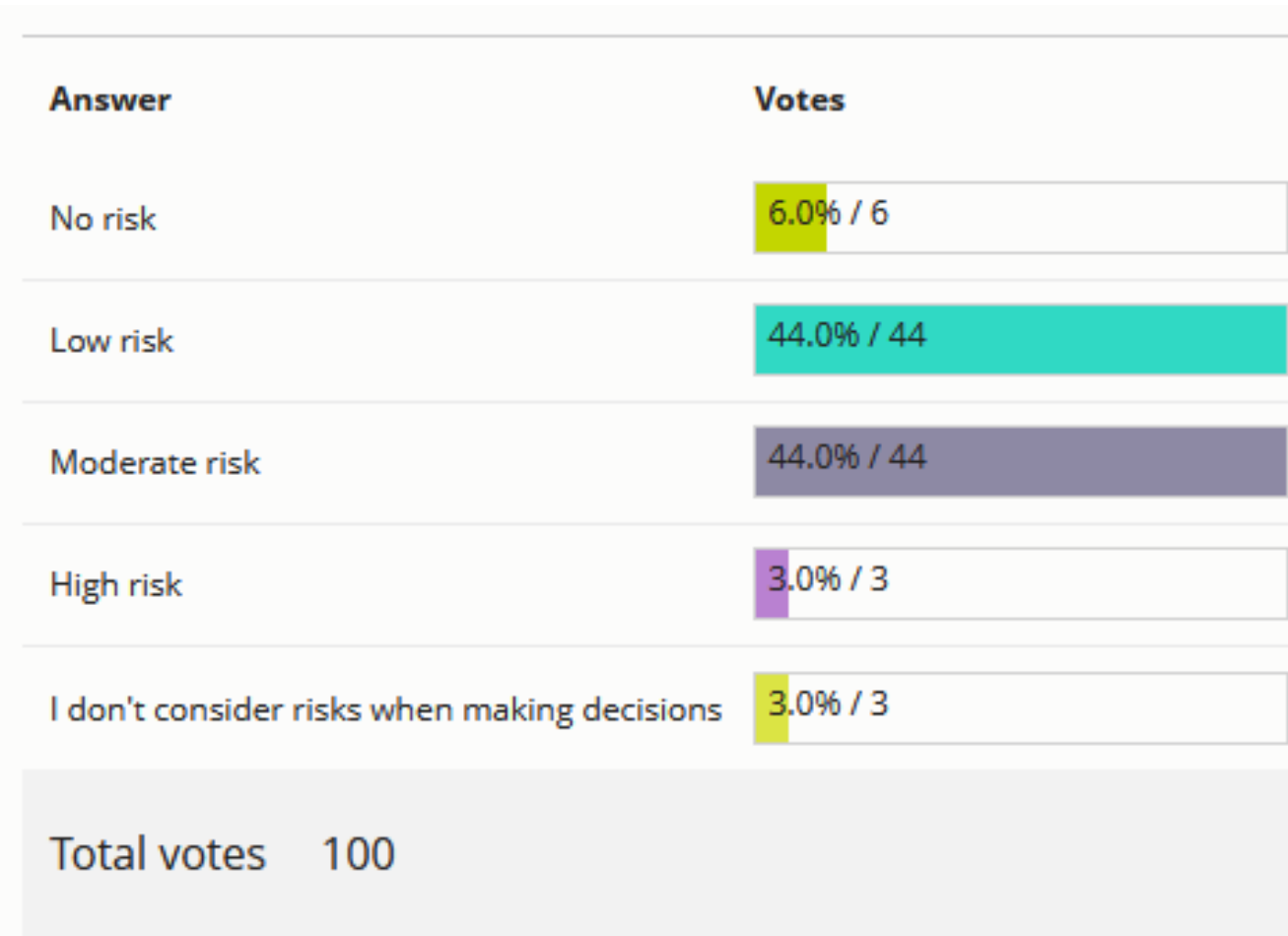
What could be your main reasons for considering participation in a clinical trial? (up to 3 options)



How important is the possibility of health benefits when deciding to participate?

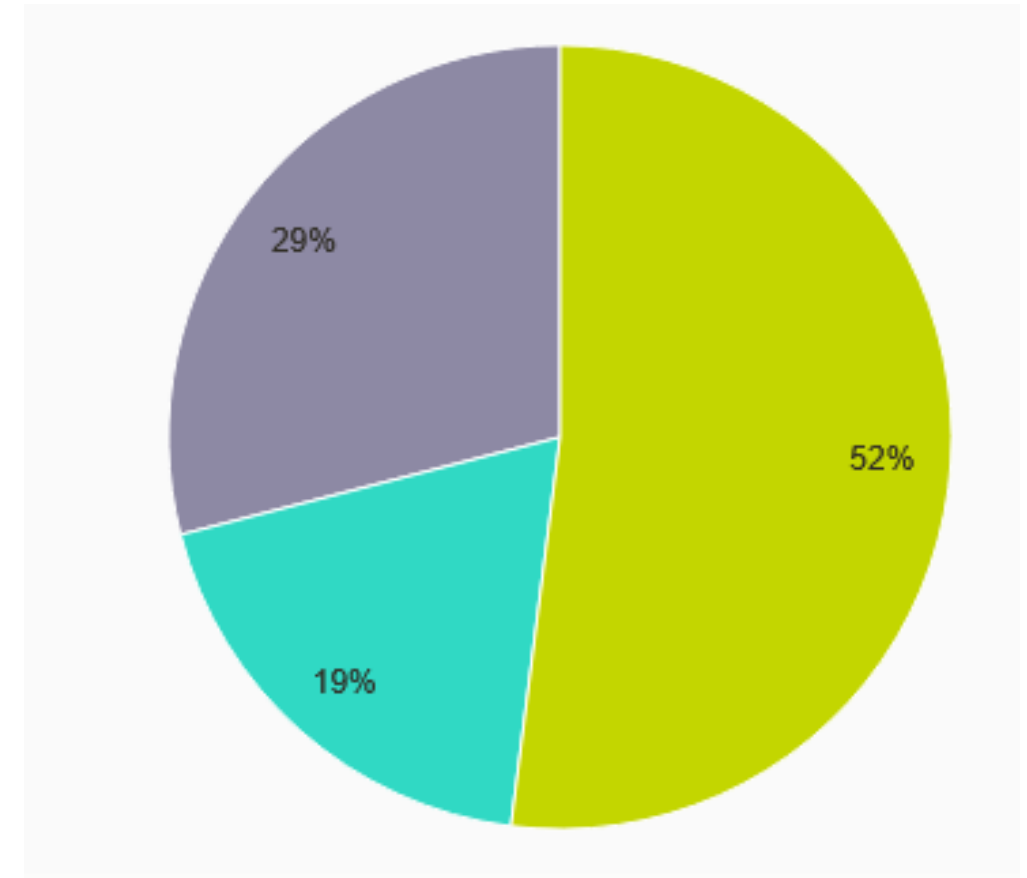


What level of risk are you willing to accept in a clinical trial?

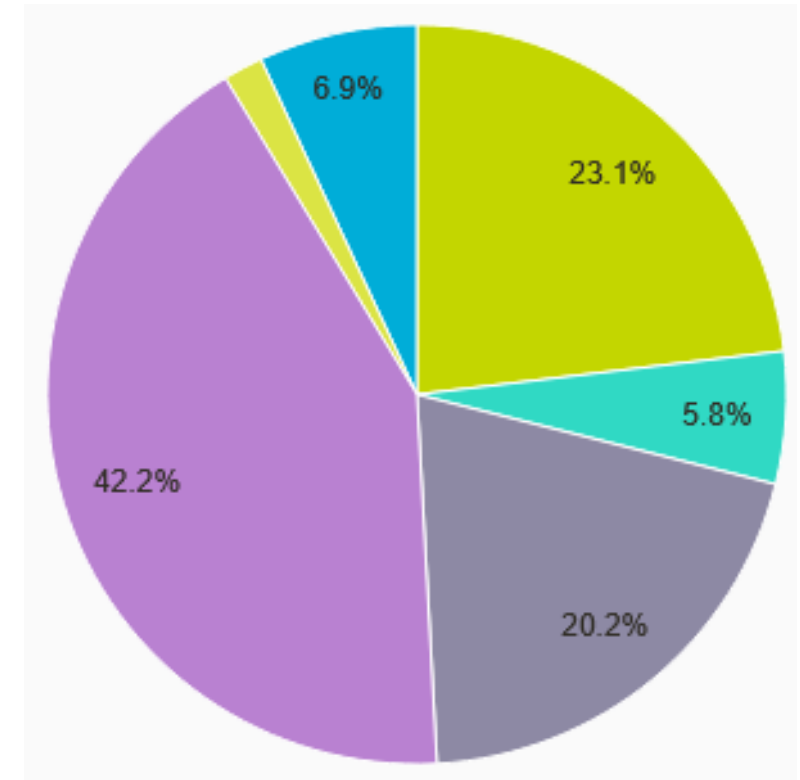
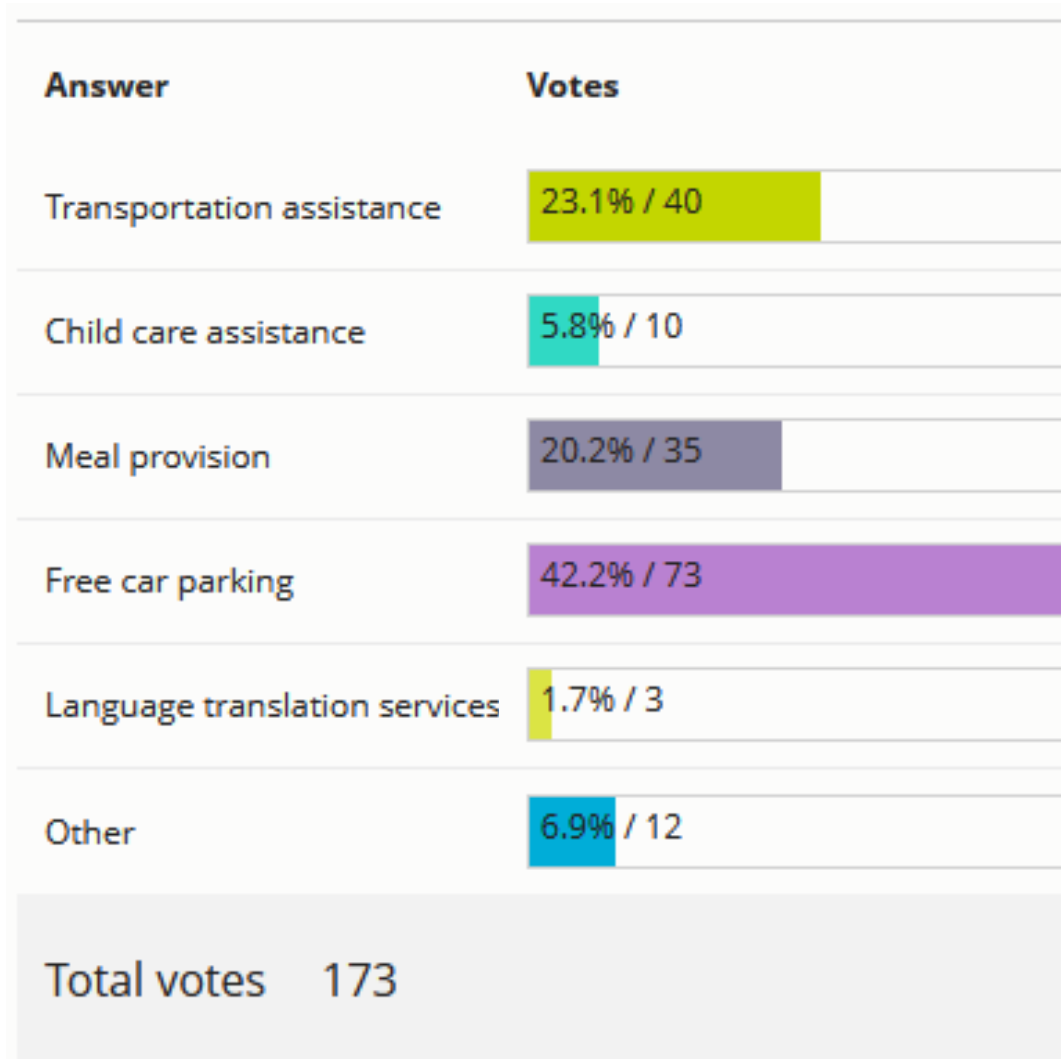


How many extra visits would you be willing to undertake to participate in a clinical trial?

Answer	Votes
As many as required	52.0% / 52
1 visit per week	19.0% / 19
1 visit per month	29.0% / 29
1 visit per year	0.0% / 0
No visits at all	0.0% / 0
Total votes	100



What type of support services would make a clinical trial appealing to you?



In your own words, what would be the ideal experience for you as a participant in a clinical trial?

Total answers 86

11th Belgian Multidisciplinary Meeting on Urological Cancers

Answers Report

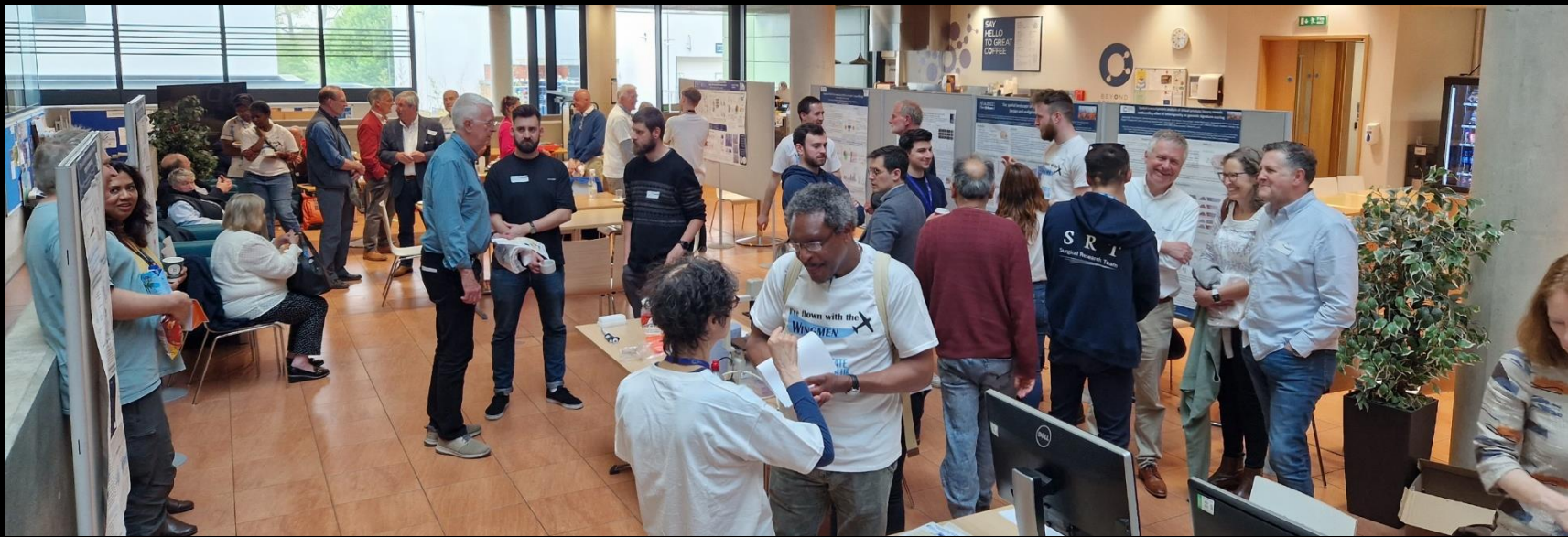
Submission Time	Answer
2024-03-15 18:53:27	Improvement in condition.
2024-03-15 14:48:21	To be treated as an individual rather than being one of many on a treatment conveyer belt
2024-03-15 14:45:58	To feel that my input really can make a difference. To know that my opinion matters.
2024-03-15 14:08:30	Clear understanding of the objective/ purpose of the trial. A low level of risk and impact on quality of life. Clear outcomes that I can support and champion.
2024-03-15 13:15:39	<u>Full information about objectives and results</u>
2024-03-15 12:33:17	That I would be getting some health benefit, or knowing it will help someone close to me.
2024-03-15 12:30:35	One whereby you have personal health feedback
2024-03-15 12:07:39	To be able to help scientific advancement with as little risk to my health as is possible and relatively little inconvenience
2024-03-15 11:49:10	I'd like to discuss the science involved, and be told about the eventual trial outcome.
2024-03-15 11:24:58	One whereby I get to assess my medical health for a specific topic like PCOS and this directly impact the approval of a new good treatment to improve woman's health.

2024-03-15 11:22:35	A successful outcome, be it to prove or disprove a medical treatment
2024-03-15 10:44:09	Personalised care that enhances the standard level of treatment
2024-03-15 10:10:26	<u>Good communication</u> and knowing what to expect.
2024-03-15 10:10:23	Good <u>clear communication</u> with reduce medical terminology such that I can have a good level of understanding throughout the process. Additionally, follow up bulletins on the outcomes of the trial where applicable.
2024-03-15 10:03:51	A successful outcome but good clinical care
2024-03-15 09:30:35	Kept well informed through the process
2024-03-15 09:29:24	To contribute to the advancement of an improved success rate
2024-03-15 09:22:03	Time to review the information prior to consent, delays in treatment/prescription minimised where possible, depending on duration of treatment knowing what options would be available to me off a clinical trial.
2024-03-15 09:01:17	<u>Being explained as much as possible what the trial is for and the possible future benefits</u>
2024-03-15 09:00:40	Probably just go with the flow!
2024-03-15 08:51:24	Participating would be important to me for a hopefully positive outcome as well as progressing the treatment for other potential sufferers as well as giving the

2024-03-15 08:48:30	I assume that I have benefitted from the research done before and therefore if anything can be learned from the treatment I have received I shall feel that I have reciprocated. Thank you.
2024-03-15 08:00:20	A comfortable area for the trial. Clear and concise explanation of the trial and possibility of side effects. Transportation assistance (I don't drive)
2024-03-15 07:57:41	To be able to help new patients and put back something to recognise the support I received .
2024-03-15 07:31:18	A process that made <u>kept me informed</u> about and as far as possible helped me feel involved in the trial.
2024-03-15 07:27:29	Productive and personal interactions with the clinicians and those managing the trial would make the experience feel worthwhile and rewarding for me.
2024-03-15 07:26:46	<u>Good personal interaction</u> , being kept informed, not too long.
2024-03-15 07:21:09	Sharing experiences with others in similar situations, and at different stages of the journey. Understanding the benefits and being able to contribute to the trial objectives. Observing or even experiencing the benefits. Seeing a trial gaining its rightful place in the treatment toolbox.
2024-03-15 07:01:21	In an area where I have concerns for myself or my grandchildren
2024-03-15 06:55:40	Information about the trial
2024-03-15 06:48:31	Knowing that my participation would contribute to better diagnosis / treatment / outcomes for patients in the future, plus possibly giving me access to treatment not yet widely available.

2024-03-15 05:58	To feel I have been personally responsible in some small way to further the advance of research in finding solutions that benefit patients and make their lives better. If I have personally benefited healthwise, that is a bonus.
2024-03-15 05:48	Understanding of trial purpose, length, value of A good rapport with clinicians, staff Information of result Assessment of potential risks before accepting and ability to pull out if becoming very unwell
2024-03-15 05:44	Worthwhile trial, good organisation, regular <u>communication</u> , genuine appreciation, information on milestones and outcome.
2024-03-15 05:40	If it took about an hour or two and at a time convenient to me
2024-03-15 05:39	For there to be a good outcome
2024-03-15 05:34	Knowing that you had made a contribution, however small, to medical science.
2024-03-15 05:27	Be offered financial compensation and be kept up to date with the details of the trial all the way to the papers publication.
2024-03-15 05:21	Being involved and informed (even if after the fact) about the outcome of the trial, and thanked for my contribution to it (even if in a control group).
2024-03-15 05:19	A better outcome than traditional treatment.
2024-03-15 05:17	To be kept up to date before, throughout and after the trial. <u>To be communicated</u> with empathy, understanding and kindness. To be regarded as a person and not just a patient. I believe it's important for consultants and medical professionals to get to know their patients as people in





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