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Summary report: A discussion about the blood cancer multiple myeloma

On 20 September 2024 we were invited by The Healing Church of God in Christ (THCOGIC) Community, based in Paddington, to deliver an online health information session on the blood cancer multiple myeloma.

Background and development of the session

This was the fifth online health awareness session held in collaboration with the THCOGIC Community. After the success of earlier online sessions, which consisted of a two-part session focused on dementia ('What is dementia?' June 2023 and 'Management of dementia following diagnosis' August 2023), and sessions on stroke (March 2024) and bowel cancer (July 2024), we were invited to identify speakers on health-related topics prioritised by the THCOGIC Community to raise awareness through online community engagement sessions.

Kelly Gleason (Cancer Research UK Senior Research Nurse, Department of Surgery and Cancer, Imperial College London) connected Professor Tassos Karadimitris with the Patient Experience Research Centre (PERC) as his research group were keen to engage with communities of African and Caribbean heritage about their research on multiple myeloma. Multiple myeloma is a type of blood cancer which can be treated to help manage the condition, but it is not curable. It is 2-3 times more common in individuals of African and Caribbean heritage and it also presents at a younger age in people of African and Caribbean heritage. In addition, patients from these communities are under-represented in clinical trials for myeloma. As several members of THCOGIC are of African and Caribbean heritage, PERC approached the THCOGIC Community Leads to establish if the community would be interested in this topic for one of their regular online health awareness sessions.

The four speakers at September's session were:

- Professor Tassos Karadimitris (Director of the Centre for Haematology and Professor of Haematology, Imperial College London and Consultant Haematologist, Imperial College Healthcare NHS Trust)
- Dr Aristeidis Chaidos (Honorary Clinical Senior Lecturer, Imperial College London and Consultant Haematologist, Imperial College Healthcare NHS Trust)
- Dr Nick Crump (Kay Kendall Intermediate Research Fellow, Imperial College London)
- Dr Katrina Fordwor (Haematology Specialist Registrar and PhD student, Centre for Haematology, Imperial College London)

Kelly Gleason also joined the session and Q&A.

Prior to the session, a planning meeting was held online with Community Leads from THCOGIC, which was attended by the session speakers and Naomi Asantewa-Sechereh (PERC) to finalise the session outline.

Attendees:

Approximately 50 Zoom accounts joined the online session, this represented individuals and families across the THCOGIC Community in Paddington but also their associated Churches in Essex and Ealing.

The audience is cross-generational and the session was attended by individuals, families and carers.

Promotion for the information session was led by THCOGIC who developed a flyer (page 2) which was disseminated across the THCOGIC network.

Format and aims of the session:

The session started with key members of THCOGIC Community welcoming the speakers and briefly highlighting to attendees why this session was important. As this is a Church community, an opening prayer and reading was done before the main presentation started.

Each speaker talked for 10-15 minutes on multiple myeloma, which spanned two themes and covered the below content:

<u>1). Introduction to multiple myeloma</u>:

- What is multiple myeloma?
- Who is at risk of myeloma?
- Ethnic and racial disparities in myeloma.
- Can we prevent myeloma?
- Monoclonal Gammopathy of Undetermined Significance (MGUS) – a non-cancerous condition which can develop into myeloma in a small number of people.
- Symptoms of multiple myeloma.
- Treatment for multiple myeloma.

<u>2). Multiple myeloma research at Imperial</u>:

- Understanding how multiple myeloma develops to identify potential targets for new treatments.
- What causes healthy plasma cells to become cancerous?
- Investigating the processes (known as gene expression regulation) that control the behaviour of multiple myeloma cells.
- Can certain DNA changes and genes increase the risk of developing myeloma in populations of African ancestry?
- Myeloma in Africa Programme: a research study investigating the genetics of multiple myeloma in Tanzania, Africa and if any of these genes are shared with people of African ancestry in the UK.

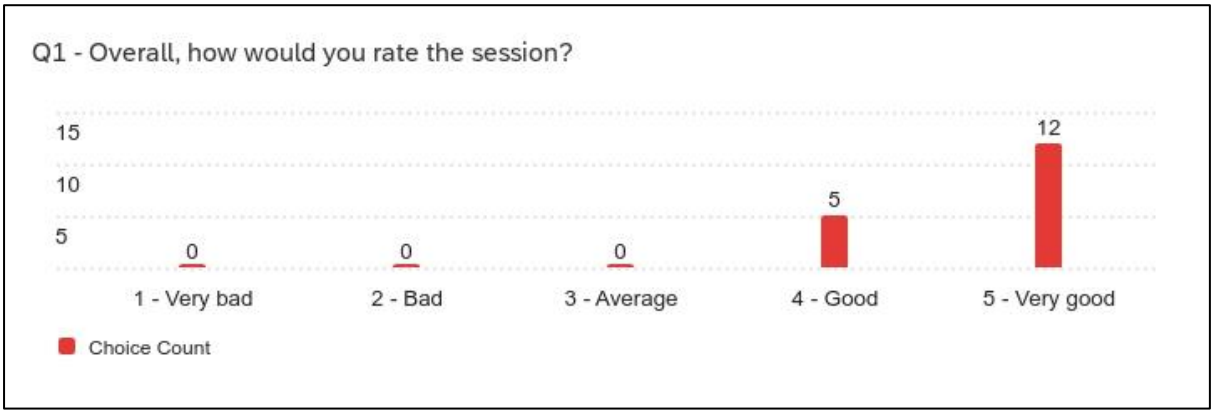
Questions were invited after each individual talk and further questions were taken after all talks. The questions asked are listed below (page 3).

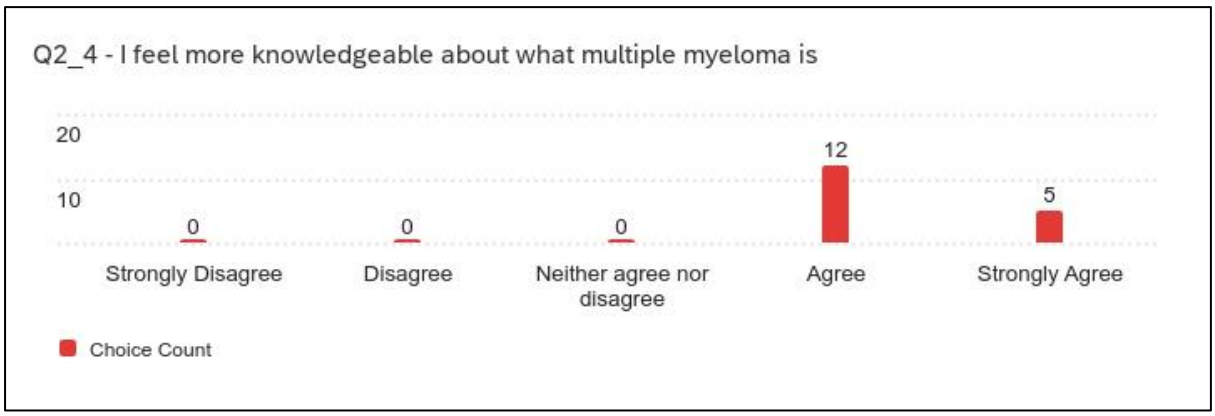
Questions asked:

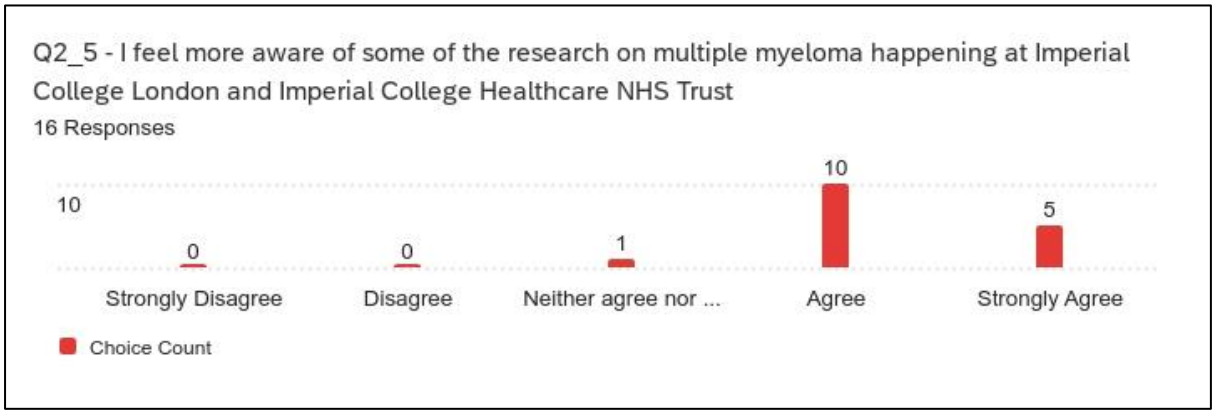
- What drugs are used to treat myeloma?
- Is myeloma more prevalent in black men or black women?
- Are there any physical signs or symptoms that one can determine that they may be developing myeloma?
- Data presented on deaths showed survival from 2017, do we have any data more recent than this?
- What is the blood test that a GP would do to diagnose someone with myeloma?
- Can someone as young as 16 years old get myeloma?
- If a person is anaemic and requiring frequent blood transfusions, are they at risk of multiple myeloma?
- Could the fact that multiple myeloma affects predominately black people from Africa and the Caribbean be linked with the malaria belt, as is commonly seen with sickle cell disorder?
- If someone has sickle cell anaemia and is diagnosed with multiple myeloma, does that make the prognosis much worse?
- What is the life expectancy for someone diagnosed with multiple myeloma?
- What are the antibodies there to do once they respond to the presence of the tumour cells, and how effective are they?
- Would a bone marrow transplant or gene therapy cure myeloma?
- You mentioned introducing new DNA, something that wasn't there before, to become an 'assassin' against myeloma – is that something synthetically made, or will it be grown from the person's body? Would this method work for other cancers?
- Does myeloma run in families (e.g. parent and child)?
- If you have lymphoma are you at risk of myeloma?
- Is it possible that myeloma pain is misdiagnosed as osteoarthritis or rheumatoid arthritis?
- Is there any evidence base in relation to life expectancy following a bone marrow transplant for myeloma?
- Can myeloma patients have more than one bone marrow transplant?

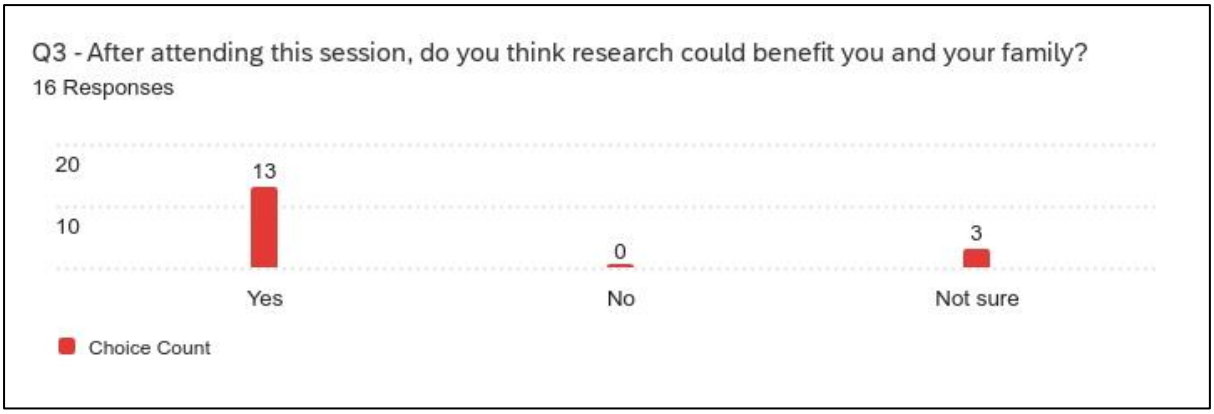
Appendix 1: Feedback from attendees

Following the session, an online feedback form was shared with the attendees. The responses from the 17 completed online feedback forms are shared below:









Q4. Do you think the information presented during the session has helped you in any way? If yes, please let us know how: (free-text)
I believe I am better able to understand the disease. 2 family members have been diagnosed in last year. One sadly passed less than a week ago.
It helps me to understand more about myeloma cancer.
more better understand of multiple myeloma.
Yes
It has helped me to be aware of multiple myeloma and has enlightened me enough to tell others about this medical condition.
It helped in giving me and my family more knowledge and hope for the future as a family member has myeloma.
Yes I gain more knowledge, information and understanding. It was great to learn how much research has been conducted.
Yes, by the age and ethnicity in depth.
The presentations have helped me have a basic working knowledge of Myeloma that if I was asked I would be able to share what i know with someone else.
Given me a better understanding and awareness.
Yes the information was very useful, as there may come a time when that information may be helpful to assist someone I know. It's always good to be aware.
I have a deeper understanding and concept of multiple myeloma.
About some of the different sign and how to go about getting treatments
Yes. I was ignorant of this cancer beforehand. Now I know the risk factors and symptoms. This awareness improves the likelihood of me noticing early signs or symptoms and seeking help. It also means I'm likely to share knowledge on this subject within my social groups. Meaning there are more opportunities for potentially detecting this cancer in its earlier stages by more people.

Q5. What did you like most about the session? (free-text)
The explanation of the disease.
The presenters know their fields and was able answer the questions asked.
The answers to the questions.
Informative and detail.

The presenters are experienced and knowledgeable. They also did it in a way that anyone could understand. The were patient and ready to answer questions in the end.
Clinical application and information about how future research may help to pinpoint type of treatments used.
In depth detail of who developed [myeloma] and the age range. Also the treatment involved.
The Q&A, as it helped to underpin and summarise what was said in the presentations. I liked the fact that the individual presentations were not long at all especially as there were 4 of them, they were short, succinct, and timely.
The way the explanations were broken down into every day comparisons and language.
It was informative, interesting and most importantly I came away with a wealth of knowledge and understanding that I did not have before.
The session gives me a greater understanding of what myeloma is and how it affects us.
It was very well presented with knowledge. All the speakers were quite clear.
It was explained in a sense where it's understood clearly.
The questions and answers session was great, because it got people talking and engaged directly with the subject matter. The types and volume of questions certainly revealed their areas of interest and concerns.

Q6. What could we do better next time? (free-text)
N/A
I think the presentation was fully recovered.
Some information could follow the most front research and treatment in the world.
Can’t think of anything.
As an addition it would be great if a one of the Nurse Specialists could share their knowledge about the day to day work and practical things that we can be aware of.
Nothing.
Overall it was very good.
Multimedia PowerPoint presentations that include things like videos, polls, etc. Quiz questions would be helpful to summarise the learning at the end of each presentation before moving on to the next presenter, to ensure clarity and to help everyone to remember the information. I think you definitely should include a patients story of living with myeloma because although good, it was 1 sided and only the medical perspective was spoken about. I would've loved to have heard from a patient whether pre-recorded or live. Nevertheless it was still very good.
Simplify some of the medical terms for the lay person.
I don't believe anything else better than how it was details.
The presentations were well paced and articulated. Sometimes the text and images were too small on the PowerPoint slides, not everyone has 20:20 vision, since you're typically communicating to an older demographic at this type of presentation. So you could improve that element.