

Science of Digestion Event Report: 26 April 2022

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Contents

Background	3
Approach and purpose	3
Event overview and agenda	3
Attendee recruitment	4
Outcomes of Event	5
Attendee numbers	5
Strengthening community and third sector relationships	5
Promoting the Imperial BRC and widening the reach of Imperial BRC community contact	s 6
Raising awareness of gut health	6
Shaping future BRC gut health research	6
Key Insight Summary	6
How community insights and feedback will be used	7
Feedback forms	7
What words would you use to describe the event?	8
What would you like to hear about at future events?	8
What could we do better?	9
Appendix 1: Science of Digestion Poster	10
Appendix 2: Public comments/questions/priorities provided at Science of Digestion Event	11
Appendix 3: Attendee demographics	15
Appendix 4: Questions raised during session by attendees	17
Appendix 5: Attendee feedback	18
Did you enjoy the event?	18
What words would you use to describe the event?	18
What would you like to hear about at future events?	18
What could we do better?	20



Appendix 6: Photos

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Background

The National Institute for Health and Social Care Research (NIHR) currently funds 20 Biomedical Research Centres (BRCs) across England. These are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate labbased scientific breakthroughs into potential new treatments, diagnostics, and medical technologies. The Imperial BRC is a collaboration between Imperial College, London and Imperial College Healthcare NHS Trust (ICHT) and is currently funded until November 2022. It has 12 research themes, four of which are cross cutting.

One of the research theme's, Gut Health, co-led by <u>Dr Jia Li</u> and <u>Professor Gary Frost</u>, wished to disseminate recent research findings to the North-West London (NWL) community which their research serves. The theme also wanted to give the public the opportunity to feed into their future research by giving the community an opportunity to discuss their concerns and needs and provide comment on what mattered to them.

The event was organised by the Imperial Patient Experience Research Centre (PERC), a core facility of the Imperial BRC, which provides public involvement advice and support to BRC researchers, in collaboration with the charity, Guts UK.

Approach and purpose

Public involvement and engagement¹ are considered to be crucial components of the development of the Gut Health theme's research agenda and their proposed future programme of research over the next 5 years.

The Gut Health theme, in particular, wanted to:

- a) present recent research developments in an informal community setting
- b) hear from members of the NWL community about their research priorities, concerns, and questions on what matters to them about gut health

Event overview and agenda

"Science of Digestion" is an event concept coined by <u>Guts UK</u>, a charity for digestive health, with which the Imperial BRC Gut Health theme jointly hosted the event. Guts UK have previously hosted "Science of Digestion" events where researchers and gut health experts speak in plain language about gut health topics relevant to the public. The events are hosted in accessible and inclusive community venues in the evenings and respond to questions from the public.

The "Science of Digestion" event was held in Ealing Town Hall on 26 April 2022 from 5pm to 7.30pm in an effort to bring together community members from NWL especially those from

<u>research/27371#:~:text=NIHR%20defines%20public%20involvement%20in,that%20influences%20and%20shapes%20research</u>

¹ NIHR - https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-



underrepresented and under-served communities². The usual Science of Digestion event format was adapted slightly in order to invite the community to tell us their gut health research priorities and questions which could then inform the Gut Health theme's future research agenda.

The agenda of the event was as follows:

- 5pm Ealing Town Hall opened to the public with:
 - A research priority wall for the public to write what was important to them about gut health (see Appendix 2)
 - Colin the Colon inflatable colon for visitors to explore to stimulate conversation (see Appendix 6)
 - o Guts UK information table
- 5.30pm Welcome and introductions (chaired by Julie Harrington, CEO of Guts UK) followed by four 10 minutes presentations (each followed by 10 minutes of Q&A) by each of the following four Imperial College research and clinical staff:
 - "500 Functions of the Liver" Dr Maud Lemoine
 - "Your gut microbes: not bad, just misunderstood" Professor Julien Marchesi
 - "IBD where have we come from and where are we going?" Dr Nick Powell
 - "Diet and your Colon: What's important?" Professor Gary Frost
- 6.50pm Open forum for the audience to "Tell us what is important to you (or write it down for us)" and ask further questions of the speakers (see **Appendix 2**).

The event was co-designed by Guts UK, PERC and the Imperial BRC Gut Health presenters. This included identifying presentation topics which would be most relevant to the public and having Guts UK review all speakers' presentations in advance of the event to ensure they were easily understandable.

Attendee recruitment

The Science of Digestion event poster (see **Appendix 1**) and email invitation was disseminated through the following routes.

Dissemination routes included:

- Guts UK newsletter
- PERC Twitter handle
- PERC Mailing List
- Imperial BRC Public Advisory Panel
- ICHT social media channels
- St Marks Hospital Patient Panel
- Southall Community Alliance
- VOICE online newspaper https://www.voice-online.co.uk/
- VOICE-global.org
- Director of Public Health for Ealing
- EKTA group

² NIHR - https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435

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- Catalyst Housing Limited
- ECTC Charity
- Young Ealing Foundation
- Ealing Community and Voluntary Service
- Ealing Mencap
- Ealing Council
- The IBS Network
- Bladder and Bowel Community <u>www.bladderandbowel.org</u>
- Walterton and Elgin Community Homes
- Notting Hill Genesis
- Groundwork London
- H4All (made up of five third sector charities: Age UK Hillingdon Harrow & Brent, DASH,
 Carers Trust Hillingdon, Harlington Hospice and Hillingdon Mind)
- Flyers circulated around the Ealing Town Hall and surrounding high street shops

Outcomes of Event

We have set out below the main outcomes of the event from the Imperial BRC's perspective.

Attendee numbers

Attendees were requested to register their attendance through Eventbrite and invited to provide optional demographic details for equality, diversity, and inclusion monitoring purposes. However, due to the number of people visiting the Eventbrite page without registering for the event, we removed the optional demographic questions in case these were presenting a barrier to people registering. However, this did not appear to be the cause of the disparity between page views and number of registrations as at the day of the event 156 people had registered with 1500 page views.

The event was attended by 66 members of the public from a wide range of backgrounds (see **Appendix 3** for demographics of those who attended and provided them when registering through Eventbrite (n=7)).

Although 156 individuals registered to attend, we are aware that these events usually attract at least a 10 to 20% dropout on the day (pre-pandemic). Having spoken to the Imperial Societal Engagement and Outreach teams an increased rate of dropout has also been occurring at their events (both on and off campus). Factors which may have also affected the registration and attendance numbers are the fact that the event fell during Ramadan which may have put off Muslim community members from attending. People may have also been hesitant about attending events with large numbers of people due to COVID 19.

Strengthening community and third sector relationships

Two families from the Hounslow Somali community (with which PERC has been establishing a relationship since July 2021) attended the event with their children who were very engaged during the event including enjoying a tour of Guts UK's 'Colin the Colon' (see photo in **Appendix 6**) with Mr James Kinross (Imperial colorectal surgeon). During the tour, one of the children said he wanted to be a surgeon! We appreciated that these families had travelled from Hounslow to Ealing especially with the event taking place during Ramadan.



Promoting the Imperial BRC and widening the reach of Imperial BRC community contacts

PERC's mailing list (for those wishing to be kept up-to-date with further involvement and engagement opportunities connected with the Imperial BRC) received 48 sign ups following the event: 43 people signed up to the PERC mailing list through Eventbrite when registering for the event and an additional five signed up at the event.

Raising awareness of gut health

The most common words used to describe the event in response to the feedback form question "What words would you use to describe the event?" were "informative" (n=29/46) and "educational" (n=7/46).

There were at least 11 children who attended the event, some of whom took part in discussions about gut health stimulated by 'Colin the Colon' (see photos at **Appendix 6**).

Shaping future BRC gut health research

Community perspectives on gut health research and the topics important to them were gathered from attendees at the event through the following mediums (these topics have been summarised below in the Key Insights Summary):

- a) questions during the event presentations and afterwards (many of these questions were recorded and are listed in **Appendix 4**)
- b) comments and questions provided in response to the following questions posted on the research priority wall (see **Appendix 2**):
 - i. "Tell us your gut health research priorities"
 - ii. "What is important to you?"
- c) feedback forms completed at the end of the event which asked the following questions (a summary of this feedback is listed at **Appendix 5**):
 - i. "What would you like to hear about at future events?" and
 - ii. "How could we do better?"

Key Insight Summary

We have summarised below the feedback provided by attendees. Full comments and questions are set out in **Appendices 2, 4 and 5.**

The main areas of interest linked to gut health which were identified by attendees via the three mediums of public feedback at the event were: the **impact of nutrition and diet on gut health** and



recent advances in this area including: how to regulate appetite; the role and impact of sugar; artificial sweeteners; gluten; fibre; food replacement drinks; different kinds of diets including vegan and vegetarian; the impact of cultural foods; weight loss; tips on how to maintain a healthy diet and gut; fasting (and its impact on certain diseases) and future working with food manufacturers. There were specific questions about what the digestive system is and how it works, certain diseases and their symptoms and treatment and management including coeliac disease, small intestinal bacterial overgrowth (SIBO), gastroparesis and inflammatory bowel disease (IBS). More information was requested about: the liver e.g., liver cysts; treatments such as peri-anal Crohn's Diseases treatment; the effectiveness of Faecal Microbiota Transplant (FMT) for ulcerative colitis; the hereditary nature of gut diseases including diverticular disease; statistics which demonstrated who and how many were affected by the various conditions including recovery rates and deaths; and the effects of COVID and obesity. The connection between the brain and the gut was popular including the impact of stress on gut problems, whether mood/anxiety affects digestion, the link between the gut microbiome and depression and the link between gut health and mental health. The gut's role in immunity was also raised, including questions about gut bacteria and its impact on skin, how to support gut microbes, pro and pre-biotics, prevention of gut disease (including for children) and the impact of lifestyle. Attendees also wanted improved diagnosis of more serious problems instead of being diagnosed with IBS. Attendees were also interested in: the link between gut health and other conditions including diabetes, hay fever, COVID, Helicobacter pylori, bile acid malabsorption, pancreatic exocrine insufficiency; and between gut health and medications including antibiotics and proton pump inhibitors. Other areas of interest included the impact of aging and gut health including the ageing gut and intolerances and children and gut health. There were practical questions such as the importance of the appearance of stool and how best to sit on the toilet. Some comments related to research more generally including how it is funded, carried out, trials, latest developments and updates on treatments and cures and whether people can get involved in research. Patient perspectives were also welcomed in future events including the social side of conditions.

Non gut health topics which were raised during the session included how to look after one's heart, whether viruses are fake, autoimmune diseases such as thyroid, psoriasis diseases and sickle cell and links between diabetes and bladder infections.

More broadly, comments related to future events which are possibly longer with smaller group talks on different diseases as well as the option to record or live stream these events for wider reach.

How community insights and feedback will be used

The attendee responses and questions will be utilised in the future to:

- inform research questions in the Imperial BRC
- evidence public priorities in funding applications
- understand aspects of gut health important to the public
- plan future events

Feedback forms

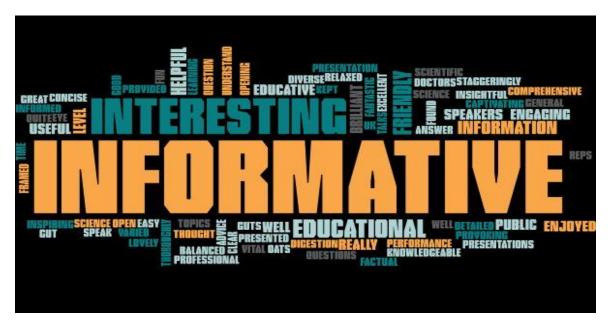
Before attendees left the event, they were requested to complete a handwritten feedback form and 46 were completed, the contents of which has been summarised below with further detail available in **Appendix 5**.



Of the 46 feedback forms returned, 89% (n=41/46) said they "Definitely" enjoyed the event with 7% saying they "Mostly" enjoyed it and one person said they were "Undecided".

What words would you use to describe the event?

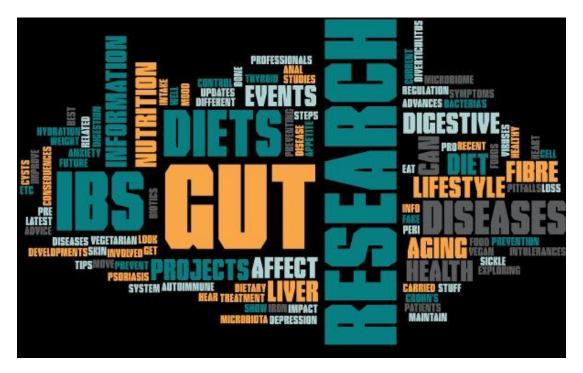
Below is a word cloud showing the words most often used in response to this question on the feedback form.



What would you like to hear about at future events?

Below is a word cloud showing the words most often used in response to this question on the feedback form





What could we do better?

The responses to this question were themed into three main categories: event practicalities; suggested topics; and session structure, the details of which can be found at **Appendix 5**.



Appendix 1: Science of Digestion Poster

The following poster was used to advertise the event.



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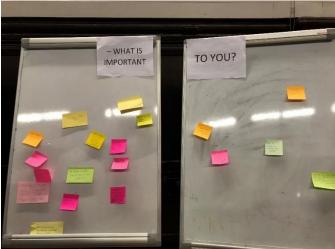


Appendix 2: Public comments/questions/priorities provided at Science of Digestion Event

The following responses were provided in response to the following questions:

- "Tell us your gut health research priorities"
- "What is important to you?"







The comments and questions provided have been themed below:

Nutrition/Diet

Questions

- Is gluten free good for the gut?
- Effects on absorption on nutrition any tips people can do to prevent this from occurring?
- If you go to the loo as soon as you have eaten does it mean you are not absorbing any nutrients?
- Can you get the fibre you need from a pill/food supplement?
- How effective are meal replacement drinks e.g. Slimfast, Buildup?
- What foods are best for my gut?
- What is the impact of fasting on ulcerative colitis, PSC, inflammatory conditions?
- Why I can't I go for long walks without the need to rush for the nearest toilet? Also there
 was a time when my homemade yogurt and kefir used to help now they make things
 worse

Comments/priorities

- The best way to cook vegetables to be absorbed and digested easily
- I would prefer more tailored talk on the effect of sugary diet than your today's measured talk brilliant and informative it was.
- My gut health has been miraculously cured by kefir!
- Artificial sweeteners and gut health
- My friend is on the toilet within 1 hour of a meal
- Certain foods make me bloated
- Diet and link with medical problems like faecal incontinence
- The research showed that drugs for IBD have limited effectiveness so could more be done with food manufacturers as diet showed to be quite effective in improving gut health

Brain/Mental health/stress

Questions

Does stress cause gut issues and problems?

Comments/priorities

- Stress and its effects on making stools turn soft
- The link between gut health and mental health
- Relationship between the gut and brain

Gut interactions with immunity

• Gut as centre of our immune centre

Gut bacteria

Questions

What does your bacteria like to do?



• What does your bacteria like?

Prevention

Questions

Should we take probiotics?

Comments/priorities

- What should kids' do to keep their gut healthy for the future
- Gut health and lifestyle
- overall prevention of disease

Specific gut health disease questions

Questions

- Can drugs (particularly) azathioprine cause (or contribute) towards the development of PSC?
- With coeliac disease why do different people have such different symptoms?
- How effective is FMT for treatment of ulcerative colitis?
- Once you have IBS does it go away?

Comments/priorities

Figures for recoveries/deaths

Diagnosis

Questions

• How can we make sure people with IBS (with diarrhoea) are tested for: coeliac disease, bile acid malabsorption, IBD (including microscopic colitis) before they're told they have IBS?

Cause of gut diseases

Questions

- Is gut disease hereditary?
- Are there any hereditary gut problems re: colitis, Crohn's, diverticulitis, IBS?
- What are the causes of diverticular disease

Links between gut health and other conditions/medications

Questions

- What links with bile acid malabsorption?
- What links with diabetes?
- What interaction with pancreatic exocrine insufficiency?
- Are my allergies (hay fever) related to my gut?
- How do antibiotics affect the bacteria in my gut?



• Do proton pump inhibitors (PPI's) affect gut health?

Comments/priorities

- Find out more about how COVID affects my gut
- Effects of gall bladder removal
- Effects of H.Pylori

Physicality

Questions

• Is there a proper way to sit on the toilet?

Stool

Questions

• It is important what my poo looks like?

Aging and gut health

Comments/priorities

- Ageing effects on: stomach, large and small intestine, ICU and rectum
- Aging and gut health/digestive system, what changes occur and how to mitigate.

Children and gut health

Comments/priorities

Kids and gut health

Research more generally

Comments/priorities

- Funding projects and events
- Research updates

Non - gut health questions

• What links between diabetes, UTI and bladder infection?

Event related

Questions

How can we mainstream this in the community?

Comments/priorities

More of this!



Appendix 3: Attendee demographics

The Eventbrite registration form for the event requested those registering to provide their demographics (which was optional) however we removed these questions from the form on 22 April 2022 in case these were preventing people registering to attend. Therefore, we only hold demographics for those who registered (and provided their demographics on registration) and who attended the event.

Table 1: Demographic characteristics provided during event registration for attendees who attended on the day (N=7)

Characteristics	n (%)
Age (in years)	
Mean (range)	37 (30-66)
Age groups (in years)	
18-24	0 (0.0)
25-34	3 (42.9)
35-44	0 (0.0)
45-54	0 (0.0)
55-64	0 (0.0)
65 – 74	1 (14.3)
75+	0 (0.0)
Prefer not to say	2 (28.6)
Gender	
Female	6 (85.7)
Male	1 (14.3)
Prefer not to say	0 (0.0)
Ethnic group	
White	
English/Welsh/Scottish/Northern Irish/British	2 (28.6)
Irish	0 (0.0)
Gypsy or Irish Traveller	0 (0.0)
Other White background	1 (14.3)
Mixed/Multiple Ethnicity	
White and Black African	1 (14.3)
White and Black Caribbean	0 (0.0)
White and Asian	1 (14.3)
Other Mixed/Multiple background	0 (0.0)
Asian/Asian British	
Indian	0 (0.0)
Pakistani	0 (0.0)
Bangladeshi	0 (0.0)
Chinese	0 (0.0)
Other Asian background	0 (0.0)

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Black/African/Caribbean/Black British	1 (14.3)
African	0 (0.0)
Caribbean	0 (0.0)
Other Black/African/Caribbean background	0 (0.0)
Other	
Arab	0 (0.0)
Any other ethnic group:	1 (14.3)
Prefer not to say	1 (14.3)



Appendix 4: Questions raised during session by attendees

The following questions were asked and answered during the event by the speakers:

- Do skin conditions give an indication of liver function?
- Do babies born with jaundice have a liver problem?
- Can the liver regenerate?
- Can having your gallbladder removed, affect your liver?
- If you are born via C section or natural delivery it can change your microbiome?
- Is kefir good for you?
- What is the cause of polyps?
- If someone has had polyps, can they get them again?
- Does doing no exercise impact having bowel cancer?
- Can Faecal Microbiota Transplant (FMT) help autism?
- Could you talk us through the differences between ulcerative colitis versus microscopic?
- Should I eat a ketogenic diet?
- Does it matter if I eat insoluble or soluble fibre?
- How much protein do I need to eat?
- How do gallstones form?

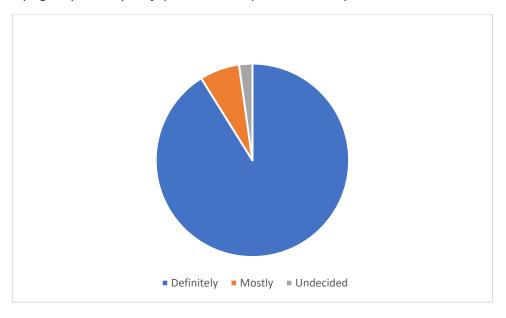
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Appendix 5: Attendee feedback

Did you enjoy the event?

Of the 46 feedback forms returned, 89% (n=41/46) said they "Definitely" enjoyed the event with 7% saying they "Mostly" enjoyed it and one person said they were "Undecided".



What words would you use to describe the event?

The responses to this question have been summarised in a word cloud set out on page 8 above.

What would you like to hear about at future events?

Below is the feedback received from this question themed into sub-headings.

Specific gut health topics

- IBS x 2
- IBS and diverticulitis
- exploring IBS/IBS symptoms
- more rare, small intestinal bacterial overgrowth (SIBO), gastroparesis
- peri-anal Crohn's Diseases treatment
- same stuff, latest developments
- research being done to show what can improve gut health
- move on liver e.g. liver cysts

Diet and lifestyle

- more on how different foods affect your lifestyle
- recent advances in diet/lifestyle preventing disease
- more dietary info/pitfalls
- food to eat

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- appetite regulation
- vegan, vegetarian diets
- how fibre diets and consequences
- more on diets and related nutrition
- weight loss,
- iron intake,
- control of diets
- more information about fibre and hydration,
- advice/tips on how to maintain a healthy gut.
- the role of diet/nutrition and associated tools to achieve good digestive health

Life course

- aging and digestive system
- aging gut and intolerances

Prevention

• prevention steps to prevent diseases

Non gut health topics

- how to look after our heart?
- if viruses are fake!
- autoimmune diseases such as thyroid, psoriasis diseases
- sickle cell

Research generally

- more about current and future research studies. How research is carried out etc
- updates on research, can we get involved in research projects?
- research progress: treatments, cures. Funding projects and fundraising events

Psychological impact

- does anxiety/mood affect digestion
- gut microbiome and depression

Gut bacteria

- the gut bacteria's impact on skin
- more information on gut microbiota,
- more about pre and pro biotics
- how best to support gut microbes

Patient perspectives

• hear from patients as well as professionals



What could we do better?

The responses to this question can be themed into three main categories: event practicalities, suggested topics, and session structure.

Event practicalities suggestions included:

- a better sound system,
- using the air conditioning,
- having more events and
- having a longer session and
- live streaming or recording the event for those who can't attend,
- providing access to the slides and
- giving more notice and
- advertising the event more widely including to local libraries and schools in area.
- allowing for online feedback

Suggested topics included:

- manufactured food
- how cultural food help/effects your gut,
- the digestive system,
- how to improve gut health i.e. which foods help gut microbe,
- more explanation about trials, research and testing and
- hearing patient voice on more issues and the social side of the conditions
- information on numbers affected by the various conditions, recovery rates, deaths, and the effects of a) COVID, b) obesity

Structure of session

- smaller group talks on specific diseases?
- samples on show of food to show comparisons
- longer session

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Appendix 6: Photos

This is a selection of photos taken at the Science of Digestion event on 26 April 2022.



Imperial Gut Health expert speakers (Dr Maud Lemoine, Dr Nick Powell, Prof. Julien Marchesi, Prof Gary Frost) and Julie Harrington (CEO Guts UK)



Science of Digestion Event at Ealing Town Hall





Colin the Colin



Inside Colin the Colon





Mr James Kinross giving a guided tour of Colin the Colon



Inside Colin the Colon

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Imperial researchers answering attendee questions after the presentations



Question to the expert from one of the younger attendees

