

# The impact of patient and public involvement in the UK Coronavirus Immunology Consortium



UK Coronavirus Immunology Consortium



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## About UK-CIC

The UK Coronavirus Immunology Consortium (UK-CIC) was a UK-wide study that aimed to quickly tackle key questions about the immune system's response to SARS-CoV-2. SARS-CoV-2 is the virus that caused the COVID-19 pandemic. UK-CIC utilised the expertise and specialist resources of 20 centres and over 200 researchers around the UK. They worked on the development of better diagnostics, treatments and vaccines for COVID-19, and to deliver real benefits to public health and improvements for patient care. Given the widespread impact of COVID-19, the views of patients and the public were central to the success of UK-CIC. The Patient and Public Involvement (PPI) panel provided advice, guidance and feedback on the progress of the research. An integral part of the consortium, the panel also gave their unique perspectives on the wider implications of findings. This ensured that the priorities for and impact of the research on patients and the wider public was considered at all stages of the project.

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## Experiences of involving patients and the public in immunology research

The UK Coronavirus Immunology Consortium (UK-CIC) was a 12-month project set up to deliver benefits to patient and public health through immunology research during the COVID-19 pandemic. The project brought together laboratory-based scientists, clinicians and the experience and unique perspectives of patient and public contributors. A Patient and Public Involvement (PPI) panel was set up to provide a platform for regular two-way conversations with the researchers. This created a space for addressing key questions about the implications of the research and discussions about what was important to the public and patient groups.

PPI in research is vital to make studies more relevant, more effective and improve the quality of research. The importance of PPI in research is becoming more apparent; however, barriers to involving people in complex fundamental science still remain. This report highlights how PPI within the UK-CIC is an example of overcoming those obstacles and negative perceptions. The report provides practical suggestions of how to bridge the gap between basic research and the lived experiences of patients and the public. By sharing experiences from the UK-CIC to show the added benefits that PPI brings to research this report hopes to encourage greater PPI in immunology research.

All members of the UK-CIC PPI panel added their perspectives and significantly contributed to the content of this report. We thank them very much for their input as well as their dedication and enthusiasm throughout the duration of the project.

# What is the UK Coronavirus Immunology Consortium?

Researchers and public contributors came together in a way never seen before as part of the UK Coronavirus Immunology Consortium (UK-CIC). Immunologists in the UK were quick to understand the central role they would need to play in our attempts to beat the COVID-19 pandemic. They realised how vital it would be to integrate public and patient views to ensure the outcomes were of highest quality, relevant to wider public health and effective in reaching their aims.

**Immunologists in the UK were quick to understand the central role they would need to play in our attempts to beat the COVID-19 pandemic.**

In March 2020, the UK went into its first national lockdown. Millions of people were suddenly asked to stay at home to prevent the spread of a novel coronavirus. 'Severe Acute Respiratory Syndrome Coronavirus 2', or SARS-CoV-2, is a virus that we knew very little about at the time. One of the unusual aspects about the virus and the disease it causes, COVID-19, was that some people became severely unwell and were hospitalised while others tested positive having never noticed any symptoms at all. It quickly became clear that understanding how the virus interacts with the human immune system would be very important if we were to beat the pandemic.

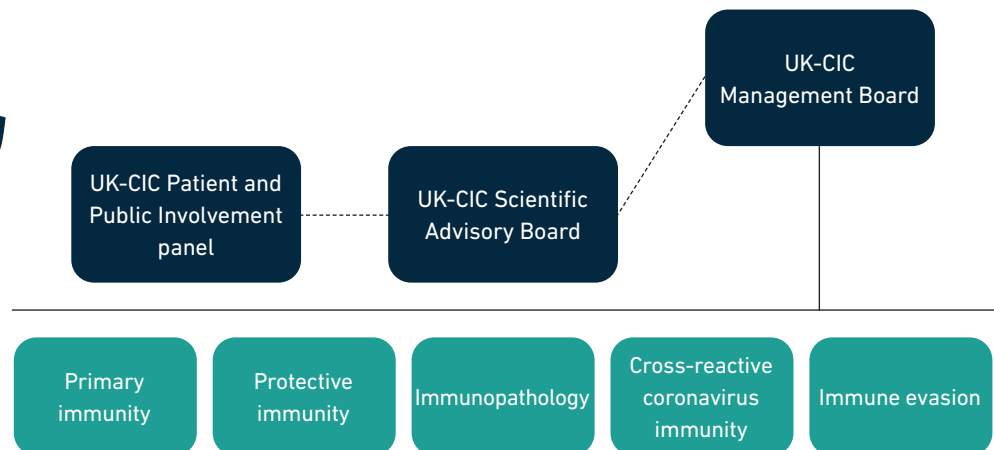
The UK is home to many of the world's top immunologists and leads the world for the quality of its immunology research. The UK was therefore well placed to launch an agile and co-ordinated research effort to answer key questions on the immunology of COVID-19. Bringing together that expertise in a nationally focused and collaborative effort would prove to be crucial if we were to make significant strides forward in our knowledge of the virus, at pace. UK-CIC was led by Professor Paul Moss from the University of Birmingham, along with a

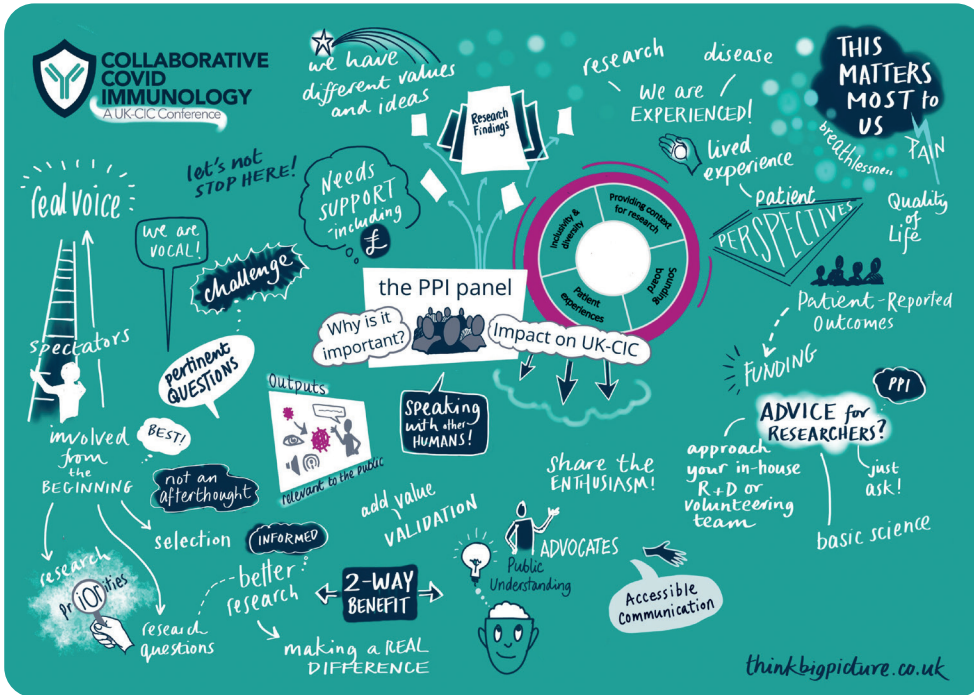
'Management Board' of expert immunologists from around the UK. The team led the five key research themes for the consortium:

- **Primary immunity:** Why are some people's immune systems better able to fight off the virus?
- **Protective immunity:** What parts of the immune system are involved in generating a protective response against COVID-19 and how long does this immunity last?
- **Immunopathology:** How does the immune system respond to SARS-CoV-2 on a molecular and cellular level and what happens when the immune system overreacts?
- **Cross-reactive coronavirus immunity:** Does immunity to previous infection with seasonal coronaviruses (which cause the common cold) alter a person's outcome with SARS-CoV-2?
- **Immune evasion:** How does SARS-CoV-2 'hide from' the immune system and how can this be tackled?



Structure and governance of UK-CIC.





The importance of PPI in UK-CIC. Illustration created from discussions during the PPI session at the UK-CIC conference, April 2021. Illustration created by Laura Brodrick.

## What is PPI?

■ Patient and public involvement (PPI) comprises research carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. The word public can refer to patients, potential patients, carers and people who use health and social care services, people from organisations that represent people who use services as well as members of the public. NIHR, School of Primary Care Research

||| This report shares evidence of the positive impact that meaningful public involvement can have on immunology research.

With £6.5 million in funding from UKRI and NIHR over 12 months, 20 centres for excellence for immunology research came together to answer these questions as part of a groundbreaking collaboration. This was carried out in close partnership with ISARIC4C, an internationally leading project, collecting and studying samples from hospitalised patients with COVID-19 throughout the pandemic. One of the ISARIC4C leads, Professor Peter Openshaw (Imperial College London) was co-Chair of UK-CIC.

Because the COVID-19 pandemic affected the whole population, incorporating the views and opinions of the public was essential to the success of UK-CIC. Involving the public in research is often described as doing

things 'with' or 'by' people, rather than 'for' or 'to' them. This report shares evidence of the positive impact that meaningful public involvement can have on immunology research.

A Patient and Public Involvement (PPI) panel was established with ten members from diverse backgrounds and a range of lived experiences. The panel was sought to offer important insight on the implications of the research being conducted. The PPI panel worked with the Scientific Advisory Board and UK-CIC researchers to give their perspectives and feedback on the progress and direction of the research. The panel members also asked relevant questions that were significant to the wider public and different patient groups. The Advisory Board, chaired by Professor Arne Akbar (University College London), gave independent advice and consultation to the 'Management Board' (see figure on page 4) as research findings progressed. They also discussed the significance of emerging global research to the consortium. Its members included prominent immunologists that were not involved in the consortium and two public contributors from the PPI panel.

## Establishing a PPI panel

**Funding the British Society for Immunology (BSI) to bring specialist knowledge and professional management to the project was crucial for the PPI function to thrive and succeed. Facilitating and developing involvement in UK-CIC research required dedicated time and resources from the beginning and throughout the project.**

**Establishing the PPI panel had to be fast-paced but cultivating PPI to become an integral part of UK-CIC was a gradual evolution. Over time, the members of the panel reported feeling more confident and comfortable in asking pertinent questions directly to the scientists. Their confidence grew in putting forward different and new questions they felt were important to be addressed. When global knowledge of COVID-19 expanded, the research undertaken by the UK-CIC progressed and the PPI panel's responsibilities developed. The panel's perspectives were vital to place the research in the context of the concerns and needs of the public to meet the changing dynamics of the pandemic.**

### Recruiting the PPI panel

The beginning of the project was run to a tight schedule due to the pandemic environment. Setting up the PPI element was an urgent priority once funding was awarded. The PPI panel had to be recruited quickly and efficiently, to be ready to seize the opportunity.

To achieve this, the BSI approached various medical research charities and organisations that had long-standing and skilled PPI groups to seek expression of interest from diverse and inclusive communities. Bringing together a group of public contributors and patient representatives with previous experience and practice in PPI was key to hit the ground running with great enthusiasm.

We created a Terms of Reference document which set out the type and duties of involvement and was used to recruit members to the PPI panel. We circulated a description of the panel's remit, aims, ways of operating and remuneration to extensive networks. Those recruited needed access to the internet, an accessible device to attend virtual meetings via Zoom and an email address for communication. It was recognised that it would be difficult to reach those who are digitally excluded but, because the project was taking place during the COVID-19 pandemic, this was unavoidable. The opportunity to be contacted via telephone was also offered. The BSI met virtually with individuals to better understand their experiences and reasons for joining the project. We then took great care to bring together a group who would complement and collaborate well with each other.



UK-CIC PPI Panel skills and strengths.

### Composition of panel

The UK-CIC public health research priorities defined recruitment to the PPI panel. The panel included people who had survived COVID-19; people from clinically extremely vulnerable groups such as people who have cardiovascular conditions, take immunosuppressive therapies or have diabetes; people from minority ethnic backgrounds; people aged 70-years-old or over; and parents with children who are clinically vulnerable. We sought members from around the four nations to represent the nature of a UK-wide consortium and there was a fair gender balance. We involved people with suitable experiential knowledge and experience, to ensure the PPI input would be appropriate and useful, which increased the potential for impact.



*All views were embraced, and the environment remained inclusive and respectful of all perspectives and ensured the panel members were a powerful voice at the table.*



A UK-CIC PPI meeting on Zoom.

“ My highlight of PPI in UK-CIC has been working with the most diverse group of people I've come across, with so many great qualities. I've enjoyed learning about the different lived experiences of our panel members and have gained an increased awareness of what is important for those patients.

Tony Kelly, UK-CIC PPI representative and Advisory Board member

The final PPI panel was made up of ten members with diverse backgrounds and experiences, and a broad set of knowledge and skills. Although a wide range of patient and public groups were successfully represented through the PPI panel, we acknowledged the difficulty of achieving genuine representation of a whole population. However, all views were embraced, and the environment remained inclusive and respectful of all perspectives and ensured the panel members were a powerful voice at the table.

### Meeting logistics

The PPI panel met on Zoom once a month and each meeting was co-chaired by the BSI and one member of the panel, which was rotated around the group. This allowed everyone a chance to gain essential skills and shared the workload between the group. The BSI led on planning of the meeting and the panel member opened the meeting with introductions and kept the conversation focused and inclusive, taking questions and managing timekeeping. The

BSI briefed each co-chair prior to the meeting to run through the logistics and worked with them to develop the meeting agenda.

Every month a different UK-CIC researcher was invited to give a short presentation on their work, with plenty of time for questions, conversations and discussions with the group. Presentations and documents were shared ahead of the meetings for panel members, especially those with accessibility difficulties, to check over. This was helpful and allowed everyone to keep a record of presentations. All meetings also covered feedback from the previous Advisory Board meeting and updates from the UK-CIC Principal Investigator and co-Chair, who alternated attendance. This allowed beneficial and high-quality interactions between the 'Management Board' and PPI panel to discuss any topics that needed advice and comment from public contributors.

We offered panel members an honorarium of £45 for each meeting as recognition of their valued contributions. This covered preparation time to read papers in advance and playing an active, engaged and constructive role in meetings. Panel members complimented the BSI's timely payment, which recognised their input and was important for authentic involvement.

“ It's important to make researchers aware that enough funding needs to be allocated for public involvement. Having prompt remuneration makes my time and efforts feel valued.

Robert Jasper, UK-CIC PPI representative and Advisory Board member

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# Activities to engage with the public

To increase and strengthen public understanding of how fundamental immunology research resulted in beneficial new ways to diagnose and treat people affected by COVID-19, the work of UK-CIC was disseminated to a wider audience. The PPI panel were involved in many UK-CIC public engagement activities, providing input and working closely with the BSI to ensure all external communications were suitable and interesting for a broad range of people.

## Making the UK-CIC website accessible for all

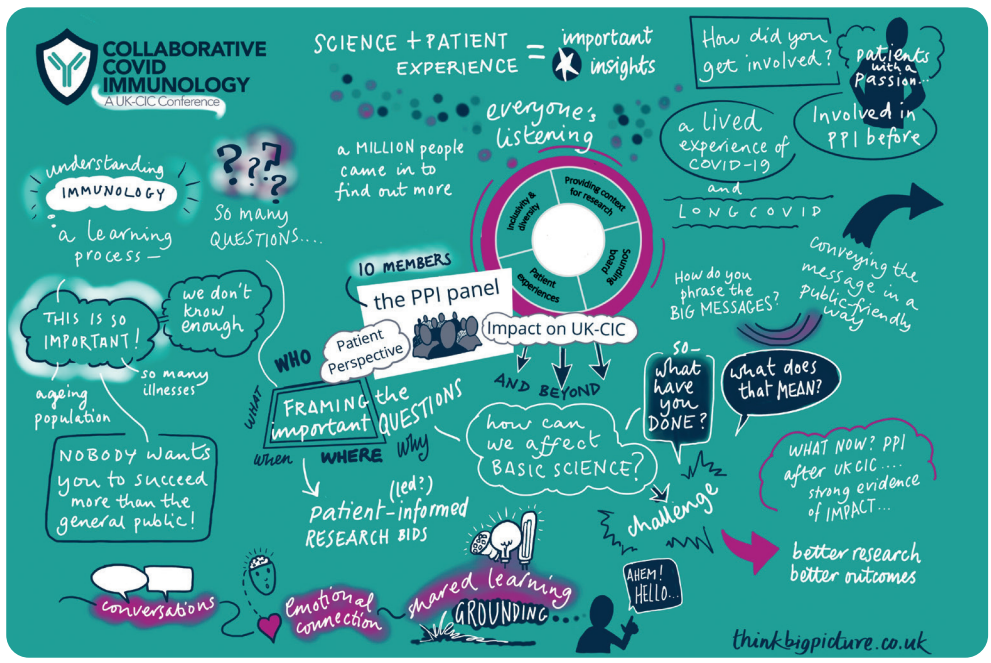
The UK-CIC website had a dedicated section for the public, which the PPI panel helped to develop. They gave ideas and suggestions on how to make the website informative, convenient to access and easy to read. It provided a selection of resources to help the public learn more about COVID-19 and immunology. As the UK-CIC progressed, more resources were added to explain the findings from the consortium. Research conducted by consortium members to understand how the coronavirus interacted with the immune system contributed to the development of vaccines. The PPI panel were concerned about vaccine uptake in their communities. They felt it important to include external resources about vaccines, such as those by the BSI addressing common questions, for the public during the pandemic.

To highlight the significance of PPI within UK-CIC, the website had a specific page prominently placed in the 'about us' section explaining

the role of public contributors. Each panel member had a profile and photo. The public were able to contact the PPI panel via email to ask any questions about the project or their responsibility within it. Additionally, two panel members featured in short inspiring videos embedded on the website and on the UK-CIC YouTube channel. In the videos they explained the importance of PPI, what it means to them personally, and how it focused research efforts to deliver real benefits and change to patients and the public. Notably, the PPI panel reviewed and approved all public summaries of the published research, providing comments on the language and style. For this they were offered additional remuneration for their time.

Through working with the BSI to improve the website, panel members were proud to be able to help their wider communities to better understand the pandemic. The BSI was praised for working with panel members to ensure the website was accessible to all who needed information about COVID-19 and immunology.

🏠 PPI with UK-CIC has been brilliant for the visually impaired community as it has led to increased accessibility of information, which is so important. All too often we are excluded from information because of lack of accessibility; this was especially true at the start of the COVID-19 pandemic. The UK-CIC website meant that we could independently digest information and that is something UK-CIC should be very proud of. UK-CIC has made science less scary and within reach for our community. Vivienne Wilkes, UK-CIC PPI representative



The patient perspective on UK-CIC. Illustration created from discussions during the PPI session at the UK-CIC conference, April 2021. Illustration created by Laura Brodrick





**Dr Andrew Filby**  
Newcastle University  
@NewcastleFCCF

**What inspires you?**  
"People who show courage in the face of adversity."

**What is your passion outside of research?**  
"Football. I am cursed to follow the 'mighty' Coventry City - a lesson in how to deal with disappointment that can come in handy when an experiment fails!"

**What did 2020 mean to you?**  
"It was a year of challenge on all fronts. We had to respond, adapt and rise up to the challenges posed by COVID-19 at home and work."



An example of a researcher profile.

### Engaging with the public

The PPI panel also helped create several activities to engage with the public about the work of the consortium to increase understanding of how basic science research can lead to public health benefits.

We held two free public webinars: 'COVID-19 and your immune system' and 'COVID-19, vaccines and protective immunity' because the PPI panel were passionate about communicating the scientific achievements of UK-CIC to larger audiences. Both events were co-hosted by a PPI panel member and the BSI, with UK-CIC researchers presenting their key findings and answering questions from the audience, which generated interesting discussions. The webinars were hugely successful with over 600 live attendees and the recordings were made available to watch afterwards on the UK-CIC website. PPI panel members were also keen to engage with the public on different platforms. For example, Reddit was used for the public to join UK-CIC researchers at an 'Ask Me Anything' event. This had brilliant engagement and after 24 hours the post had received 605 comments.

The PPI panel often discussed the unbalanced public perception of researchers during the pandemic and wanted to showcase scientists in a human light. From this idea, profiles of UK-CIC researchers were created for social media with short, engaging and fun facts about the people behind the lab coats.

### PPI was central to the UK-CIC virtual conference

Patient and public involvement with immunology research was a noticeable feature

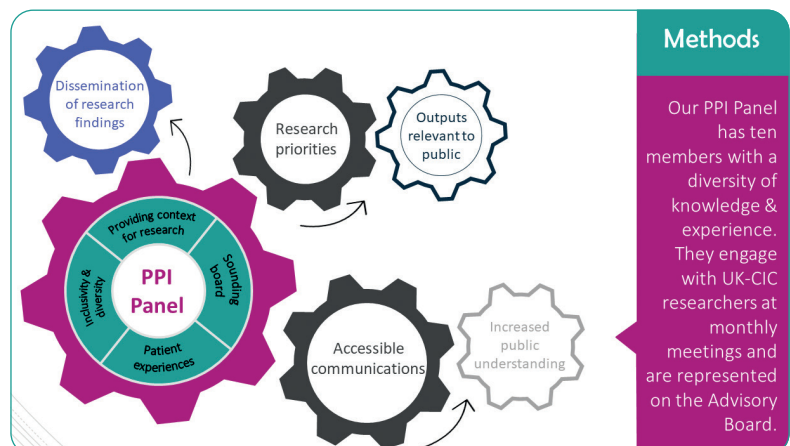
Part of the PPI poster presented at the UK-CIC conference on engagement methods used for PPI.

As a researcher I find I can learn a lot from PPI; there's excellent work happening here which I hope will continue. I really enjoyed Tony's power-packed 5 minutes – really important message!  
UK-CIC conference delegate feedback

at the UK-CIC scientific virtual conference 'Collaborative Covid Immunology', held on 28–29 April 2021. The conference was aimed at academics, but PPI was a visible theme throughout and had dedicated sessions outside of the main scientific programme.

After a recommendation from the PPI panel, all scientific abstracts had to include a public summary to make the complex research more understandable. On both days of the conference, there was a PPI 'chat room' where public contributors and researchers could meet informally to discuss the importance and power of PPI and hear patient perspectives on UK-CIC research. These sessions were well attended with interactive and thought-provoking dialogues, which were captured by an illustrator in eye-catching diagrams and can be seen throughout this report.

A subgroup of the PPI panel created a poster about the impact PPI had on UK-CIC and presented it during the conference, engaging attendees in conversations about the methods and practicalities of meaningful involvement. Prominent in the conference programme, a PPI panel member, Tony Kelly, gave a powerful speech about the value of PPI in research and the meaning of genuine two-way partnerships between researchers and patient and public groups. The speech, a highlight of the conference to many, was seen live by 209 delegates and later shared on the UK-CIC website and social media.



## Successes of PPI in UK-CIC

**It was evident that PPI within UK-CIC impacted on the researchers, the research, and importantly, the patient and public contributors. Building in funding for a PPI panel to value involvement and ensure effective expert administration and management of PPI were crucial to success. Fostering relationships and facilitating quality interactions between the PPI panel and researchers required time and commitment to the project from all parties. Through creating an open and inclusive space to explore diverse views and a wide range of perspectives, PPI influenced researchers' ways of thinking about their work and impacted future research questions about COVID-19 immunology.**

### Influencing UK-CIC leadership

Two members of the PPI panel were part of the UK-CIC Scientific Advisory Board and played an active role in representing the public and patient voice at their meetings to consult with the UK-CIC senior management. This ensured PPI was always present at the leadership level and embedded in the wider UK-CIC priorities. The UK-CIC research theme leads engaged with the PPI panel, exploring how the lived experiences could influence research questions and what the findings meant for patients and the public.

We used the poll function on Zoom during online meetings, which allowed the Advisory and Management Boards to provide regular anonymous comment on PPI, in a quick and easy manner. At the January 2021 Advisory Board meeting, 70% reported that the feedback from the PPI panel had changed their views towards the research agenda of UK-CIC. This positive response increased to 90% by June 2021, showing the evolution of PPI within UK-CIC culture and how the panel's perspectives became more recognised over the course of the project. Extremely positively, all the Advisory Board members agreed that: the impact PPI had on UK-CIC had been valuable or extremely valuable; the input from the PPI panel provided a novel perspective on UK-CIC research which may not otherwise be considered; spending funding on PPI was value for money; and because of their experience with PPI in UK-CIC

*Part of the PPI poster presented at the UK-CIC conference on the successes of PPI within the consortium.*

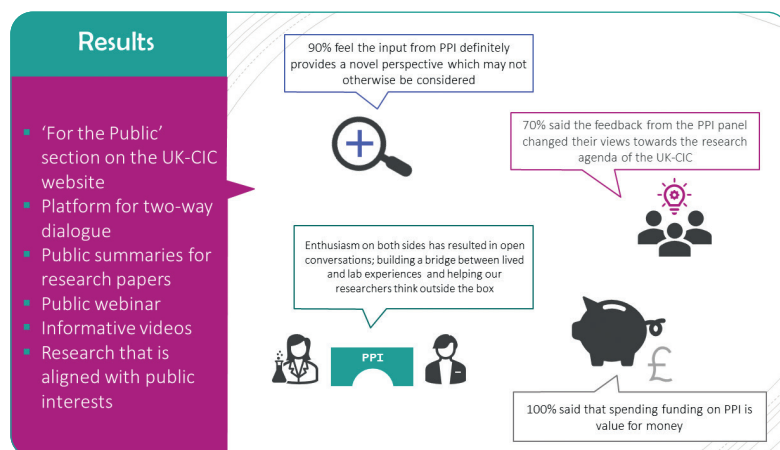
*The UK-CIC research theme leads engaged with the PPI panel, exploring how the lived experiences could influence research questions and what the findings meant for patients and the public.*

**“PPI helps to make sure we think through the ultimate application of our research for the public. This can initially be challenging to address and so it may even make scientists feel a little defensive. But like all things in life, after you apply yourself, you learn from it and it makes you stronger.”**

**Paul Moss, UK-CIC Principal Investigator**

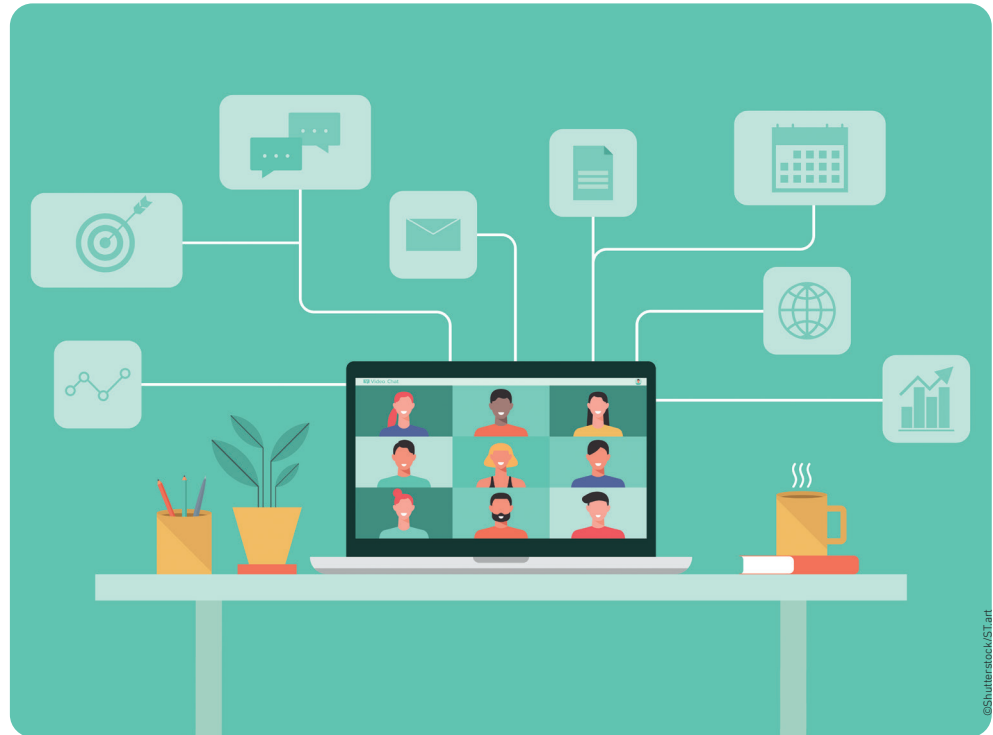
they would consider including PPI in their own future research projects.

Encouragingly, towards the end of the project, 83% of the Management Board agreed that the impact PPI had on UK-CIC had been valuable or extremely valuable; 67% felt that the input from the PPI panel provided a novel perspective on UK-CIC research which may not otherwise be considered; 83% said that spending funding on PPI was value for money; and 83% said that as a result of their experience with PPI in UK-CIC they would consider including PPI in future research projects.





*After meeting with the PPI panel, researchers reported finding the meetings rewarding, useful, enjoyable and valuable, and many commented on how welcoming, engaged, and knowledgeable the panel was.*



### Impacting directly on UK-CIC researchers

Through the PPI panel meetings, researchers were provided with a platform and sounding board to have honest conversations about their research priorities. Valuing individual experiences and discovering different perspectives on research findings ensured that the outputs of UK-CIC were relevant to the public and aligned with patient interests.

After meeting with the PPI panel, researchers reported finding the meetings rewarding, useful, enjoyable and valuable, and many commented on how welcoming, engaged, and knowledgeable the panel was. It was also mentioned that the meetings were challenging but constructive and the panel were working with researchers to be critical in the right way. The format of the meetings was praised, which focused on the panel's views and

allowed time for thoughtful, relevant questions. Better understanding the usefulness of PPI, some researchers felt motivated to include more patient and public involvement and engagement in their work.

The PPI panel ensured that equity, equality and diversity featured meaningfully at the meetings and that underserved communities were placed at the forefront of discussions. Researchers commented that their experience with the panel made them reflect on how they talk about patient cohorts and the use of patient samples, which needs sensitive and clear language. Communicating their findings to the PPI panel was also an opportunity for researchers to assure people that their basic immunology research was relevant to the public during the COVID-19 pandemic.

*“I found the PPI panel stimulating and enlightening and without a doubt improves the quality of our research.”*  
Alex Richter, UK-CIC researcher



Highlights from speech made by PPI representative Tony Kelly (pictured above) at the UK-CIC conference in April 2021. Illustration created by Laura Brodrick.



Researchers were prompted to seek new collaborations and apply for further funding to work on ideas generated from the conversations with the panel.

### Shaping COVID-19 immunology research

Conversations started at the meetings between the PPI panel and UK-CIC researchers were able to guide future research questions about COVID-19 immunology. The impact of PPI on how scientists think about and approach their work is often difficult to measure as it can be subjective. But UK-CIC researchers reported that discussions with the panel helped them to learn from a range of experiential knowledge. Hearing about the lived experiences of individuals with long COVID, autoimmune diseases and other long-term health conditions, caused researchers to think differently about future work needed to better understand

patient perspectives. Interactions with the panel made researchers consider which questions were most important to the individuals affected by COVID-19 and afforded them the occasion to assess the bigger picture of the context of their work.

Additionally, researchers acknowledged the importance of involving patient and public perspectives from the start of a research project and that they would strive to embed PPI at the start of future grant applications. Researchers were prompted to seek new collaborations and apply for further funding to work on ideas generated from the conversations with the panel.

- “ The conversations with the panel made it easier for me to think about what we’re doing in terms of the individual people it might impact (and what they want) rather than just thinking about populations.  
Sam Wilson, UK-CIC researcher
- “ The questions we are addressing were deemed important by the panel, but they also had lots of other highly useful suggestions. I found it extremely rewarding and took away 2 pages of notes!  
Tracy Hussell, UK-CIC researcher
- “ PPI has bridged the gap between lab and lived experience and UK-CIC has proven that personal experiences have a place within basic scientific projects.  
Lynn Laidlaw, UK-CIC PPI representative

### Being part of something powerful

An evident impact of PPI within UK-CIC was on the individuals of the panel. Their involvement provided them with something meaningful to be part of during the COVID-19 pandemic, which was an emotional and difficult time for everyone. Being personally involved in efforts to bring the pandemic under control and gaining new knowledge of basic research, immunology and COVID-19, panel members felt empowered, valued and listened to. Public contributors reported that it was a privilege to collaborate with scientists that were prominent in UK media and as Government advisors during that period.

Many panel members cited that their positive experience in UK-CIC increased their confidence in PPI as well as knowledge of PPI by learning from each other. This unintended impact was an important motivator for public contributors to remain involved in the project. This was reflected in retaining all ten members of the panel for the duration of the project as well as a high average 90% attendance at every meeting.

### Building relationships

Another success of PPI within UK-CIC was the relationships that formed between researchers and the PPI panel and the great sense of teamwork in everything that was achieved.

Building this strong rapport required financial resources, time, and facilitation by the BSI. It was vital to manage the relationships carefully, including being reachable and responsive by email and phone, and having efficient administrative support to schedule meetings, distribute agendas and documents, and take minutes.

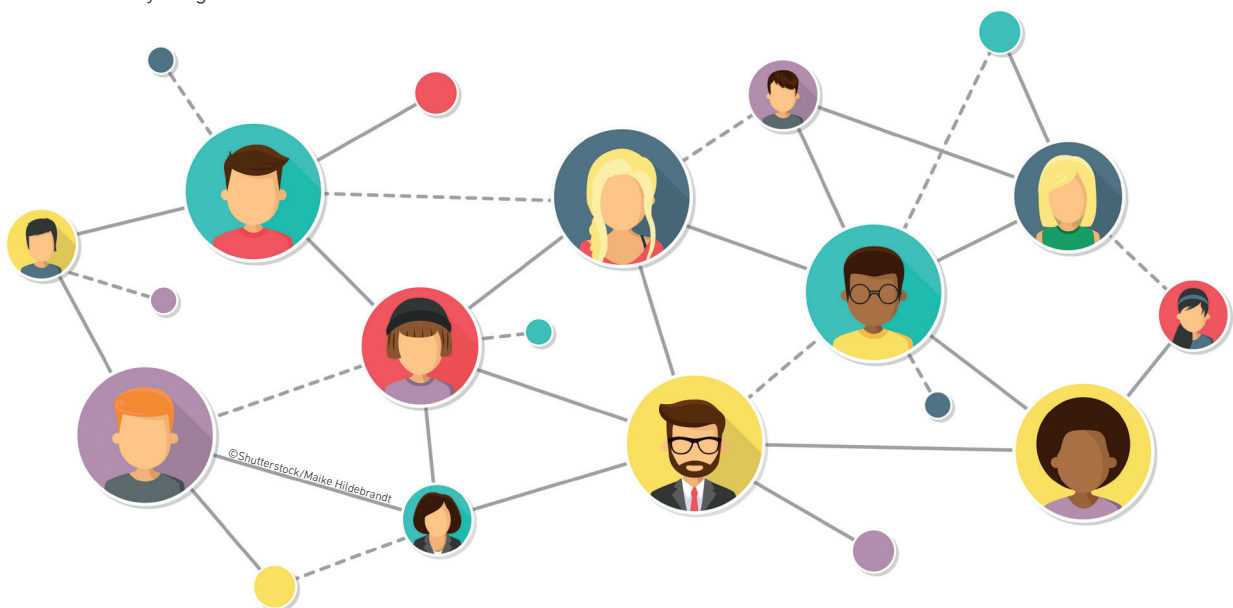
“Working with UK-CIC has made me proud of PPI. I want to now promote my experience to encourage others to work more with research. I've been reading up on the huge amount of information about immunology and have enjoyed learning about the endless research which is happening at UK-CIC.”  
Mo Hafeez, UK-CIC PPI representative

“Working with the PPI panel has been a privilege and I've appreciated seeing the relationships develop between all parties. There's a mutual respect between the researchers and PPI representatives, which has been the foundations of impactful and meaningful involvement.”  
Erika Aquino, UK-CIC PPI lead

“It has been wonderful to witness the energy and commitment that the PPI panel has brought to the project.”  
Doug Brown, UK-CIC Advisory Board member



Public contributors reported that it was a privilege to collaborate with scientists that were prominent in UK media and as Government advisors during that period.



## Learning from experience

Through sharing best practice and exploring the practical resources and support needed to embed meaningful PPI into a research project, this report hopes to encourage others to fund, adopt and champion PPI in basic science, particularly in immunology research. As well as highlighting successes, it's important to examine the lessons learned from UK-CIC experiences and activities that should be actively taken into account in future immunology research.



*PPI should be considered before the initiation of a research project and involvement of patients and the public needs to happen from the start when formulating research questions.*

### Embedding PPI

Integrating PPI into the UK-CIC project occurred in an evolutionary, as opposed to instantaneous, way. It took time for the researchers to recognise the important role of the PPI panel, but they did come to see that their involvement supplemented and enriched the work of UK-CIC, and PPI became established as a fundamental element of the project. Through bringing together scientists and public contributors to learn from each other, the experiences of UK-CIC helped debunk the myth of 'us versus them' in science. The PPI panel meetings provided vital, high-quality interactions between PPI contributors and researchers and proved that working collaboratively rather than in isolation was more effective. In the UK-CIC, the Advisory Board and senior leadership team truly championed PPI and influenced a change in attitude towards PPI, which allowed PPI to become embedded in the immunology research culture.

*“In the early stages of the project, PPI was met with some reluctance with many researchers having no experience in PPI previously. However, over time the contributions from the PPI panel became more and more appreciated. The researchers really took the importance of PPI to heart, and this change of mindset happened among many UK-CIC researchers.”*

Arne Akbar, UK-CIC Advisory Board chair

### Evaluate and improve

A valuable lesson learned was the importance of regularly evaluating PPI throughout the project. After each meeting, anonymous feedback was gathered from the panel to questions such as 'What went well? What did you enjoy?' and 'What could be improved? What can be done differently next

*“When I discovered what the research was going to be about, I thought it was purely academic and not related to halting the pandemic, so I didn't have any great expectations for the PPI. As the year progressed, I understood how the academic research helped understand the virus' effects on the immune system which contributes to beneficial treatments for patients, proving that UK-CIC research is worthwhile.”*

Robert Jasper, UK-CIC PPI representative

time?'. Responses and suggestions were used to improve future meetings and the comments and actions taken were reviewed with the panel every three months. For example, initial panel feedback suggested some researcher presentations were too technical and so future presenters were briefed beforehand to minimise jargon and acronyms and fully explain any graphs. The panel later praised the clear communication and disciplined plain English approach of presentations.

Assessing and improving the PPI experience continuously was useful to identify any challenges and what had to be modified to overcome them. This was helpful when conversations diverged away from the remit of UK-CIC research. Understandably, many panel members were worried about COVID-19 vaccine hesitancy within their communities but it was commented that these discussions became unfocused. Addressing the feedback, we overcame that challenge by inviting UK-CIC researchers who worked on COVID-19 vaccination to speak to the panel



and reiterate the fundamental immunology of vaccines. Revisiting the aims of UK-CIC research and explaining how basic immunology research could deliver benefit to public and patient health successfully refocused the PPI panel and clarified the relevance of UK-CIC.

### Lessons for the future

PPI in the consortium was very successful overall, but when the leadership team were asked what they felt were barriers that prevented PPI from achieving maximum potential impact within UK-CIC, feedback included lack of knowledge about PPI within UK-CIC. An essential way to improve PPI impact in any research project and something that could have been improved in this case was to partner with public contributors to provide training for researchers before and during the project, covering what PPI is, why it's important and how best to do it. Increased awareness and understanding of PPI within UK-CIC would have benefited the project and more researchers could have sought to interact with the panel.

The application stage of the project moved quickly when there were many unknowns about COVID-19 and it was understandable that research priorities were set by the researchers and independent scientists. Ideally, PPI should be considered before the initiation of a research project and involvement of patients and the public needs to happen from the start when formulating research questions. However, this was the pandemic environment UK-CIC had to work in, and recruiting the PPI panel came after funding was awarded and the BSI was appointed to manage the PPI function. This is



*Researchers must not ignore or overlook the significance and relevance of PPI and instead consider it a mutually beneficial relationship.*

an important lesson learned for UK-CIC. Many of the researchers, after meeting the PPI panel, mentioned that it would be very useful to talk to patients and the public when designing funding applications.

### Final thoughts

Conducting meaningful PPI with basic immunology research can be achieved within urgent, critical research conducted during a pandemic situation. We have shown that impactful PPI is not only possible but that it can be accomplished with exceptional results and exceed expectations through the UK-CIC. Crucial to this success was building in funding for a PPI panel from the start, as well as effective expert administration and management to support and facilitate relationships between researchers and the PPI panel.

Through sharing best practice and examining the practical resources necessary to embed PPI, this report has shown that involving patients and the public can enhance research and dispel the misconception that PPI in basic science is 'difficult'. The experiences shared are evidence of the invaluable contributions from patients and the public from all backgrounds. Researchers must not ignore or overlook the significance and relevance of PPI and instead consider it a mutually beneficial relationship.

The UK-CIC project has laid the foundations for PPI in immunology research and this should now be built upon for the advantage of future basic scientific research. PPI can impact greatly on laboratory-based research when given the opportunity to do so.

📌 *PPI is here, ready and waiting to be involved.*  
UK-CIC PPI panel



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