

De-mystifying Immunology to Reduce Diagnostic Delay in Immunodeficiency

Detailed Project Outline

Contents

Aims	1
Outputs and outcomes	2
1. Immune Health Public Engagement Gala and Tour	2
2. School student research projects	3
3. Resources for GP awareness of immunodeficiency	4
Importance and Expected Impact.....	5
The key people we want to reach.....	6
The engagement team	7
Project delivery	8
Project Evaluation	10
Costs Requested by Wellcome.....	11
Timeline for Project Delivery	13
Key Findings from Student Focus Group.....	14
References	15

Aims

Our overall aim is to reduce diagnostic delay in immunodeficiency through engagement activities that increase understanding of immune health. Early identification of immunodeficiency will reduce infections, antibiotic use and hospital admissions, as well as improving length and quality of life.

To achieve this we aim to:

- 1) Enhance the basic knowledge of immune health in a large number of individuals from the general public through specific engagement activities
- 2) Facilitate engagement with immunology in school and medical students through a schools research taster course
- 3) Increase awareness of immunodeficiency in primary care through GP-devised education packages

Immunodeficiency may be primary (PID) / genetic (which is relatively rare, average incidence being 7.6 per 100,000 live births in the UK [1]) or secondary (SID) (increasingly common due to modern medicines and an ageing population). Both result in recurrent, severe and unusual infections that reduce life expectancy and impact on quality of life. This is exacerbated by diagnostic delay which is 7 years for PID [2]. Shortening this time would improve quality of life for example by reducing time off work or school from illness and also life limiting damage to body caused by infection. There has been only recent awareness of the increasing frequency of SID and how this impacts on an individual and more collectively on health service utilisation. Infection accounts for 11% (5.3 million) of all NHS bed days. The patients most at risk of admission are those with chronic disease and an associated SID [3]. Earlier recognition of the immune deficiency would allow earlier intervention or prevention, leading to reduced morbidity and mortality for patients, reduced antibiotic use and reduced hospital admission.

We consider the main barrier to timely diagnosis of these complex and sometimes devastating diseases is a lack of awareness amongst the general public and health care professionals. To address this we propose a package of coordinated public engagement activities to promote awareness of immune health and to empower undiagnosed patients and healthcare professionals. We have a unique opportunity to deliver our main outcome because Birmingham has won the bid to host the European Society of Immunodeficiency (ESID) meeting in October 2020. This will be hosted at the International Convention Centre in Birmingham which is a busy public thoroughfare and is collocated with the Library of Birmingham, the most visited attraction outside of London [4], where our public engagement activities will be hosted.

The main outcome of this study is to increase awareness of immune health with the aim of reducing diagnostic delay in immunodeficiency. Our strategy is multi-pronged as we recognise that accessing and engaging GPs alone is challenging due to their time commitments, breadth of knowledge required in many disciplines and that it is often the patient that asks the question 'is there something wrong with my immune system'? We recognise that we need to engage and inform the wider public to ensure a basic knowledge of immune health, but to close the loop we also need to provide enhanced engagement targeted to health care professionals and develop a legacy by breaking down barriers to studying immunology in school and medical students selecting immunodeficiency as a specialism. This strategy aims to get the general public to present to GPs when there is a problem with their immune health and then for GPs and other health care professionals to diagnose or facilitate referral in a timely manner

Outputs and outcomes

We will achieve our overall aim through the following 3 work packages:

1. Immune Health Public Engagement Gala and Tour

We will develop reusable engagement materials that can be used with the general public during the ESID 2020 conference and reused to tour around medical facilities to promote awareness of immune health in patients and their families. We will create an **Immune Myth-Busting Pop-Up Shop** in collaboration with Sense About Science. The pop-up shop will be launched as part of our public Immune Health Gala during ESID 2020 and will then tour to medical facilities such as Birmingham's Queen Elizabeth Hospital. The event will be promoted through internal and external University and

hospital channels including using previously successful immune health fliers with headline 'Sense Behind the Science' facts. The stand will be staffed by researchers, immunologists and *Ask For Evidence* ambassadors who will guide visitors through the evidence behind the hearsay, answer questions and deliver short '**soap box science**' talks. This multi-platform engagement will include:

- I. **Physical props** will be created with a message (e.g. orange juice – "can vitamin C cure the common cold?" which will be informed by our preliminary work with Sense About Science linked to the Ask For Evidence campaign).
- II. **Quizzes and games** to test and explore knowledge by completing quiz games such as; '**Bad luck versus bad health**' and '**How to boost the immune system**'. These quizzes will be a fun and interactive way for visitors to engage with the research, but will also help us to evaluate the effect of the interaction and inform us about immune health beliefs that can be used to target engagement with patients going forward.
- III. **Patient voices**, which will be heard through all threads of this application. At the conference specifically they will be voiced through short '**pill box patient**' talks from some of the 600 patients who attend ESID (IPOP is the integrated strand for patients), plus screens and posters with patient testimonials. We are supported in this endeavour by PID UK - a national patient group that have contributed to this application. They will also disseminate materials created as well as a survey to reassess diagnostic delay for immunodeficiency in the UK. All involved patients will have the opportunity to attend ESID sessions for free.
- IV. **Immune health exhibition**. We have secured the opportunity to continue our presence in the **Library of Birmingham** for two months after ESID by displaying information, dissemination materials and visuals from the project in the main public exhibition space.

The ICC and Library of Birmingham are offering their public space to our bid because this work correlates with Library of Birmingham / Birmingham City Council aims to support projects that improve health and wellbeing for Birmingham residents.

2. School student research projects

We recognise that attitudes to immunology in young learners is a key area where engagement is needed. Therefore, we plan a **hands-on immunology research taster-project** at the University for Year 12 school students who are from widening participation backgrounds and have an interest in studying medicine. Our project design was developed in collaboration with local Year 12 students that contributed to a focus group and the University of Birmingham Outreach Team to ensure maximum value and accessibility for students taking part. This work-package will comprise:

- I. **A hands-on laboratory research project**. Delivered over 4 months and including three full day sessions at the University of Birmingham Medical School to offer highly desired 'real university experience'. The students will work in small groups to design and deliver projects to test the change in immune parameters to stimuli such as a glass of 'immune boost' orange juice or a 10 minute jog which are claimed to boost immune health. Their experiments will involve detecting changes in levels of circulating free antibody light chains in saliva to determine which stimuli, if any, elicit a response and whether this correlates with what is claimed to boost immune health. (N.B. absolute levels of free light chains in and of themselves are not indicative of any positive or negative health outcomes).

- II. **A literature, media and public research project.** The students will collect data on perceptions about immune health versus published findings. For example; interviewing friends and family, auditing adverts and products in shops and studying research papers. This independent study will be supported through our online learning platform CANVAS and through giving students access to the University Library for the duration of the project.
- III. **Mentoring** by medical students who have already undertaken their immunology module. This provides a unique opportunity for medical students to develop important teaching, mentoring and engagement activities and was seen as highly valuable by the focus group.
- IV. **Conference poster creation and presentation.** All students will be invited to present their projects at the **Immune Health Gala in the Library of Birmingham** linked to the **prestigious ESID 2020** conference. Students will also have the opportunity to attend conference sessions and present their projects to and interact with a panel of immunology experts. All school cohorts from which our students will be selected will also be invited to the Gala and students will also be encouraged to invite others so their work can be presented to friends, family, teachers and school colleagues in addition to the wider public.

3. Resources for GP awareness of immunodeficiency

We recognise that GPs are key in translating raised awareness around immunodeficiency into reduced diagnostic delay. However, traditional approaches to raise awareness, such as face-to-face teaching, have low uptake and coverage of the GP cadre in UK. Therefore we will develop novel resources that work for GPs, are created with GPs and are engaged with patient experiences to address this essential third strand of work. Our planned **collaboration with GPs** (for which we already have several recruits) will be key to determining the details of this plan through which we will deliver:

- I. **A GP CPD resource, supported by the Royal College of GPs**, delivering bite-size practical guidance on immunodeficiency that mirrors the short consultation period GPs have and the diversity of symptoms with which immunodeficiency patients present. The format (on-line, written or face-to-face) will depend on our work with GPs, but the material will cover the whole diagnostic journey from presentation to implementation and interpretation of routine tests (the FISH campaign, is a mnemonic for key immunodiagnostic tests already published but not widely circulated) that can triage onward referral.
- II. **GP surgery materials.** To include a patient-facing 'Top 10 symptoms' leaflet that a patient can take into a consultation and GP-facing leaflets including 'at risk patient' information including the key FISH diagnostic tests. These resources will be developed with our patient and GP collaborators.
- III. **Access to ESID.** All GPs who use the CPD material, including those involved in development, will be given free registration at the ESID conference and the opportunity to meet with world-leading immunology specialists and get up-to-speed on the latest in immunodeficiency.

We will optimise all of the outputs produced to ensure a wider and lasting legacy. All materials created will be publicly accessible on a **dedicated project website and disseminated through social media outputs**, but also through our key partner platforms and more widely at science festivals and through collaborative activity with Sense About Science. We will also make the most of every opportunity to co-create content and generate dialogue within the project. Carrying out this project to coincide with ESID also provides a valuable and unique opportunity for clinicians, patients, GPs and the general public to come together and engage around immunodeficiency, which we expect to have a lasting effect on participants. We will also collect evidence and evaluate all stages of our activities, including baselines and employ the expertise of The Audience Agency to help with our analysis. Our medical student mentors will also be offered the opportunity to help carry out and learn about public engagement evaluation during the Gala. This will allow us to not only properly evaluate our efforts and plan further activity, but also to produce reports and other outputs for dissemination amongst interested groups such as; public engagement professionals, immunology researchers, medical outreach groups, and healthcare organisations.

Importance and Expected Impact

Approaching the problem of immunodeficiency through public engagement represents a novel and innovative approach. However, it is one that we feel will be successful and impactful, given the wide range of causes and contexts for immunodeficiency and the persistent myths and confusion within multiple groups around immunology and immune health. In summary, our project will

- Empower the general public to challenge claims about immune health in their everyday lives using evidence and research and to seek advice from a medical professional where they believe they may have a problem with their immune system.
- Support patients to have their voices heard by healthcare professionals and the general public about their experiences of immunodeficiency, which they may not have felt empowered to do previously due to the complex and poorly understood nature of these diseases.
- Increase confidence in A-level and medical students, especially those from widening participation backgrounds who face more competition than their peers to gain entrance to medical school and the best careers in medicine, to pursue studies and careers in immunology and immunodeficiency research careers.
- Create a lasting effect on the students involved, whether or not they continue into medicine and/or immunology in talking to others, within and outside of their studies and careers, about immunology research.
- Empower GPs to be confident in a) recognising, diagnosing and referring patients with symptoms which raise suspicion of PID or SID and in b) accessing and utilising current research on immunodeficiencies and understanding and using local and national immunology patient and clinician networks.
- Create lasting networks amongst immunodeficiency researchers, the public and patients and build a legacy of engaged immunodeficiency research at the University of Birmingham and beyond.

Beyond the two years of this initial project, we also hope to build our work in this area further. Using this work as a basis to translate public engagement around immunodeficiency more broadly within the UK and beyond. Although SID incidence is increasing rapidly in the UK mainly due to issues that are more prevalent in developed countries, such as cancer treatments and ageing, immunodeficiencies are also responsible for a massive burden in the developing world. For example, the biggest global cause of SID, protein-calorie malnutrition, can affect up to 50% of people in some communities [5] and it is estimated that there are 6 million people with PIDs worldwide, of which 70-90% are undiagnosed [6].

The key people we want to reach

The general public: We want to improve knowledge of immune health in a large number of people to enable individuals to make appropriate decisions on seeking healthcare advice or self-help strategies. 'Boosting your immune system' is common parlance through UK winter months but evidence in the public domain is often confused or overstated. To do this we want to reach a proportion of the 0.5 million individuals who walk through the International Convention Centre over the 5 days of the conference and the 2.2 million patients and their families who are treated annually by the UHB NHS foundation trust. This strategy will access a large unselected cross section of Birmingham's ethnically diverse society. Additionally, a large number of the 'general public', who are friends, family and teachers of the students involved will be invited directly to the Gala event and will be motivated to find out more and find the experience more memorable due to the link to the students involved.

Students: This study aims to raise awareness of immunology, in school and medical students, and break down barriers to careers in this field because it is perceived to be complex and difficult to relate to clinically (focus group and other literature). Increasingly cancer and autoimmune diagnosis and drug treatments require manipulation of the immune system and so it is important that our next generation of doctors and scientist are comfortable with immunology and its application. We want to break down barriers to science and specifically immunology learning by offering school students a project that is hands on, 'real-world' and applicable, delivered by inspiring teachers – factors an MRC report in 2011 highlighted as being positively viewed in young people's attitude to science. Those positive teachers will be medical students from the University of Birmingham. These are students already engaged in science but that we want to cultivate an interest in immunology and science education as a strategy to improve knowledge of immunodeficiency in doctors and a long term aim would be to maintain recruitment into Clinical Immunology as a medical specialty which has been challenging over the last 5 years. Presenting the student projects at the Library will continue the meaningful dialogue around immunodeficiency within schools and families and give students further confidence through their role as immune health 'experts' within their families and friend groups and in helping people they know to challenge immune claims.

General practitioners are the coordinators of patient care in the NHS and the key contact point for most patients when they seek health advice. They are often not confident in advising or testing for immunodeficiency and immunology is often seen as a specialised or difficult area. We recognise that we need to support GPs and other doctors in responding to the question 'is there something wrong

with my immune system'? We know this is important as UK Immunologists run regular educational events around immunodeficiency and these are often poorly attended, we believe because immunodeficiency is not a priority to GPs partly because the enormous spectrum of diseases it entails and the undiagnosed incidence of immunodeficiency is not well understood. Therefore engaging GPs through this project has the potential to lead to positive benefit for patients, GPs and the NHS alike in terms of earlier diagnosis and fewer repeat GP visits.

The engagement team

The team brings together a unique collaboration of patients, clinical immunologists, academics and public engagement professionals to deliver a meaningful engagement project for the first time on this scale for immunodeficiency. Birmingham is a key geographical area for primary and secondary immunodeficiency; it has a diverse ethnic population, hosts a centre for rare diseases and is a major clinical and research centre for other rare, immune related diseases through Birmingham Health Partners (University of Birmingham, Birmingham Women's and Children's Foundation Trust and University Hospitals Birmingham Foundation Trust). The University of Birmingham is 3 miles away from the ICC where ESID 2020 is due to take place and has a committed [public engagement strategy](#) supported by Wellcome Trust ISSF funding, which this project aligns closely with in promoting culture change and capacity building in public engagement at the University of Birmingham. The University of Birmingham Outreach Team will also be closely supporting this project by a) training medical students to work with our students (including child protection), b) offering their expertise and networks, which reach over 200 Birmingham schools, during the recruitment of and liaison with students, including set-up and oversight of student access to CANVAS and Library Services. Additionally we will be collaborating with Sense About Science, for whom one of the University Public Engagement Team is already an Ask For Evidence ambassador to focus on immune health claims and to create our pop-up shop, which can be used a wide variety of settings that are mutually beneficial and provide a unique way for the public to learn how to challenge claims that they come across.

Dr Richter is a clinical Immunologist and Senior Lecturer. Experience of meaningful public engagement includes a widely cited national survey of allergy in British Bee Keeper, chairing the UoB anaphylaxis UK patient group which facilitates medical students' training schools and clubs in anaphylaxis management and speaking at regional patient days, hospital members' forums and GP educational events. She also contributes regularly to patient engagement days. She has a wide portfolio of teaching activities including being module and programme lead and developing an extensive range of immunology and immunodeficiency educational material. Through PIDUK she promotes patient advocacy and experience in medical school education inviting patients to deliver lectures on their experience of immunodeficiency and also the role of patient groups in rare disease.

Dr Huissoon is a clinical Immunologist and chair of the ESID local organising committee. He led the successful bid for ESID 2020 meeting in Birmingham, with increasing public awareness of Immunodeficiency as a key component of the bid. He has supported patient voice as chair of the medical advisory panel of the Primary Immunodeficiency Association patient support group 2008-2013 and developed bi-annual regional immunodeficiency patient awareness and engagement events 2008 to date. He has undertaken school engagement through the "BloodLabs" pathology in

schools project: where he designed and delivered this large interactive event for year 8 at Ninestyles School in September 2015 and undertook public engagement training through RCPATH/Science Museum in 2014. He has undertaken regional television and radio appearances, including an annual radio phone-in slot with Ed Doolan. He has hosted public seminars on allergy and is a Sense About Science member and contributor. He also represented the Allergy Garden for the Royal College of Pathologists at the Chelsea Flower Show, 2017, where he discussed allergy (and plants) with visitors.

Mrs Bennett is a member of the patient network, PID UK, whose mission is to support and represent people affected by PID in the UK by working with healthcare professionals and other relevant organisations to improve their care and quality of life. PID UK will bring experience in clear written information for patients and communicating this through a variety of media. They have existing experience of raising awareness and understanding of immunodeficiency within the medical profession, lobbying for improved patient care and promoting research into immunodeficiency.

Project delivery

Steering Group: Strategic oversight of the project and timeliness will be coordinated through the steering group delivered by the PI Dr Richter (0.1 FTE), a dedicated Project Coordinator (1.0 FTE), Dr Huissoon, the chair of the ESID 2020 local organising committee, Mrs Bennett on behalf of PID UK, and a member of the UoB Public Engagement Team.

Delivery of the three work-packages will be organised as follows:

Public Engagement Gala and tour: Gala will be delivered by the above team in conjunction with other UK and European Immunologists, researchers including a designated Post-Doctoral Fellow (0.4 FTE) and medical students who will be trained by the Post-Doctoral Fellow, Dr Richter, the UoB Public Engagement Team and Sense About Science.

Schools Research Taster: The Schools work-package will be delivered by Dr Richter, the Project Coordinator and the post-doctoral student. This work will be supported by the UoB Outreach Team who have already been consulted on feasibility and willingness to contact the widening participation schools that UoB collaborates with. UoB Medical Students will also be involved in mentoring our students.

GP / patient awareness and educational material: will be developed in collaboration between Dr Richter/Huissoon, GPs who are supporting the project and promoting the material through the Royal College of GPs and PID UK. Support for organisation and administration of this work-package will also be provided by the Project Coordinator.

Evaluation: will be built in throughout the three work-packages and will be developed by the UoB Project Coordinator with support from the UoB Public Engagement Team. Help in evidence and data collection will be provided by Medical Student volunteers and assistance with design of evaluation and analysis and interpretation of the findings will be provided by The Audience Agency who will be employed as short-term consultants.

Summary of project timeline (more detail can be found on page 12)

April 2019	Project commences.
April 2019-April 2020	<p>Patients interviewed to explore experience and gain testimonials.</p> <p>GPs interviewed to explore experience of immunodeficiency and successful awareness campaigns they have responded to.</p> <p>Disseminate patient survey through PID UK to get an up to date assessment of diagnostic delay in the UK.</p> <p>Develop all materials for project to generate key outputs.</p>
April 2020	Pilot GP and primary care patient awareness materials.
June-July 2020	Deliver Schools project
October 2020	Deliver ESID 2020 engagement project
November 2020 April 2021	<p>Collate, reflect and disseminate multi-source feedback.</p> <p>Plan future engagement strategy.</p>
April 2021	Close project

Risk management: the project includes a number of vulnerable individuals including children and patients with chronic disease. This project has been developed in conjunction with the UoB Ethics and Governance Department to ensure all aspects of the project are safely delivered. Considerations have included the ethics of undertaking research projects with minors and the appropriate DBS checks required, consideration of the human tissue act, and the possibility of and mitigation for an unexpected findings in the schools research project.

Recruitment for the student project is likely to be over subscribed. Our work with the UoB Outreach Team and Y12 students has suggested that there is huge demand for University access sessions that are provided on campus, particularly where these are hands-on laboratory projects and having the unique opportunity of presenting work to leading immunologists. Students will be asked to apply for this project by submitting an application form in the December prior to the project beginning as this is when they apply for other widening participation schemes. We will then work with the UoB Outreach team to assess and select applicants who are likely to benefit and bearing in mind any other schemes they have applied for. We will not select based on pre-existing interest in immunology/ immunodeficiency as we would like to assess the impact of the activity on those who would not have considered immunology for further study or careers. However, those who happen to have an existing interest will not be excluded, instead we recruit regardless of level of interest and assess and compare interest pairwise between the baseline and at the end of the project.

Developing material for GPs by GPs is the way we feel we are most likely to improve awareness of immunodeficiency. There is a risk that the material created will suit 'engaged' GPs but we will assess the implementation of the material and learn from its success or failure to guide future strategy.

Again, we will carry out pairwise comparisons to allow us to interpret whether pre-existing interest is a factor in outcomes.

Project Evaluation

We will gather evidence and evaluate our work in order to determine our success against our outcomes for all three work-packages. We will use a range of quantitative and qualitative methods in each case and seek external guidance from The Audience Agency on our plans before any evidence is collected. In each case we will formulate a baseline and then assess each groups' response both immediately after the relevant intervention (e.g. after taking an online course or face-to-face session for GPs) and at the very end of the project in order to assess longer-term impacts of participation. We also hope to continue this work beyond this project to assess effects on diagnosis rates and uptake of immunology study, for example.

Our evaluation plans for each work-package are outlined below:

Effects on public and patients through Immune Health Gala Event and touring activity

- PID UK patient survey to assess average times and path to diagnosis
- Collection of patient testimonials and stories analysed for themes and used to create testimonial videos and posters and 'pill box patient' talks
- Footfall counts for those who attend and those who take part in different activities
- The Myth-Buster Pop-Up shop will have integrated evaluation e.g. for each item visitors will guess whether it has any effect on immune health before revealing the evidence behind the claims
- Interactive quizzes and games to determine underlying knowledge, beliefs and interest in immune health. Carried out in Library of Birmingham and GP surgeries in the lead-up to the event to help shape work on 'pop-up' shop and other activities during the Gala and to inform interaction with the public going forward
- Post-activity responses collected during Gala through collection of vox-pops, games, and questionnaires carried out by medical student volunteers and Public Engagement Team
- For all evaluation respondents will be stratified into groups including patients, friends and family of students, clinicians etc
- Responses to Ask For Evidence call outs before and after main event for submissions of claims related to immune health (before) and any stories of challenging immune claims afterwards as well as looking at page views etc for related web content on the Ask For Evidence website
- Social media analysis and web traffic / downloads analysis
- Contact cards with details of web contact form given out to all participants to let us know of any longer-term outcomes (e.g. the experience leading people to look for evidence behind immune claims or booking a GP appointment). Not likely to yield a large number of responses, but any received would be very informative
- Specific questions to be added to conference post-event survey to assess value of project to clinicians and patients attending for the conference
- Media coverage

Effects on students through taking part in research-taster course

- All participating students will be asked to fill out questionnaires to assess their interest and understanding of immunodeficiency research before, immediately after and several months after the project. This will measure a) confidence and experiencing in discussing immune health with others (e.g. family), b) specific learning about immunodeficiency, c) likelihood to study or consider a career in immunology d) applications and outcomes to higher education (collected with Outreach Team to avoid overlap)
- Participating medical students will be surveyed to see whether they might be more likely to specialise in immunology as well as to collect feedback about impact of being involved

Effects on GPs through developing and undertaking CPD activities

- Feedback from our GP focus group will be collected and worked directly into the creation of CPD materials
- Evaluation will be built into any materials e.g. face-to-face or online sessions would include 'role play' scenarios for GPs to decide whether they would suspect immunodeficiency based on a consultation and what action they would take
- We will also evaluate GPs' self-assessed confidence in immunodeficiency including accessing and telling patients about research
- A number of GPs that are not otherwise involved (including no involvement of other GPs at the practice they work in) to compare reported rates of queries from patients about immune health and any subsequent actions between those in which fliers and patient information developed as part of the project are and are not available

Costs Requested by Wellcome

Total expected cost: £218,560.

(including £40,000 expected additional funds from sponsors and 10% contingency of £16,232)

Total requested funds: £178,560.

Salaries: Total £119,689

Dr Richter: 0.1 FTE in kind

Dr Huissoon: in kind

Margaret Bennett / PID UK: in kind

Project Co-ordinator: 1.0 FTE 'Grade 6' salary of £29,799, including on-costs, 24 months = £79,935.40

Post-Doctoral Fellow: 0.4 FTE 'Grade 7' salary of £35,551 including on-costs, 24 months = £39,753.86

UoB Public Engagement Team: Partially funded through Wellcome Trust ISSF

Ask For Evidence ambassadors: in kind from Sense About Science

Fees: Total £4,500

Graphic designer / art worker: (co-produced printed materials and exhibition) £250/day 8 days = £2,000

ICC venue hire = free

Library of Birmingham exhibition space = reduced cost at £2,000

ESID 2020 attendance fees for GP partners, medical students and participating students = free as part of engagement strategy for meeting

RCPGP accreditation fee (1 activity for 1 year) = £500

Materials and Consumables: Total £13,600

Printed materials: Fliers (key signs and signposting, FISH test for GPs), posters, patient testimonial materials, students' research posters, holders for fliers, banners (equates to approx. 10,000 fliers, 100 posters, 8 exhibition panels, 8 banners and contingency for holders/fixing materials) = £6,000

Laboratory consumables for student research taster (£20 per 30 students) = £600

Laboratory testing and light chain kits provided in kind = free

Pop-up shop materials - to cover example items, shelving, 'till' and shop structure, related printed explanatory materials/panels etc. Based on previous experience with 'Think Corner' pop-up shop project and pop-up shop guide = £7,000

Production costs, press and marketing: Total £15,500

Advertising / promotion budget / website design, hosting & maintenance = £15,000

Video/Photography for posters and testimonials = £500

(Plus partial contribution through additional funding from sponsors)

Travel and subsistence: Total £5,000

Support for school student colleagues and families to attend on the day of Schools gala (coaches from school and subsistence at gala evening) and students' travel on to campus = £5,000

Evaluation and dissemination: Total £4,039

Evaluation support (eg collating questionnaire data) – 6x students employed through University of Birmingham 'Worklink' during event for 10 hours each (£10 per hour, 8 hour shift plus training time, offered first to medical student mentors) = £600

iPads (6 total but 3 in kind for UoB PER team) £313.00 x 3 = **£939**

Reports and dissemination activity including Engage conference to and PER team activity = in kind

Audience agency 5 x days work (£500 per day) = £2500

Contingency: 10% Total £16,232

Expected additional funding: Total £40,000

This will support the Schools gala event, printed materials and reagents for the research taster project and production of materials for the GP surgeries and CPD.

The Binding Site = £15,000

CSL = £25,000

Timeline for Project Delivery

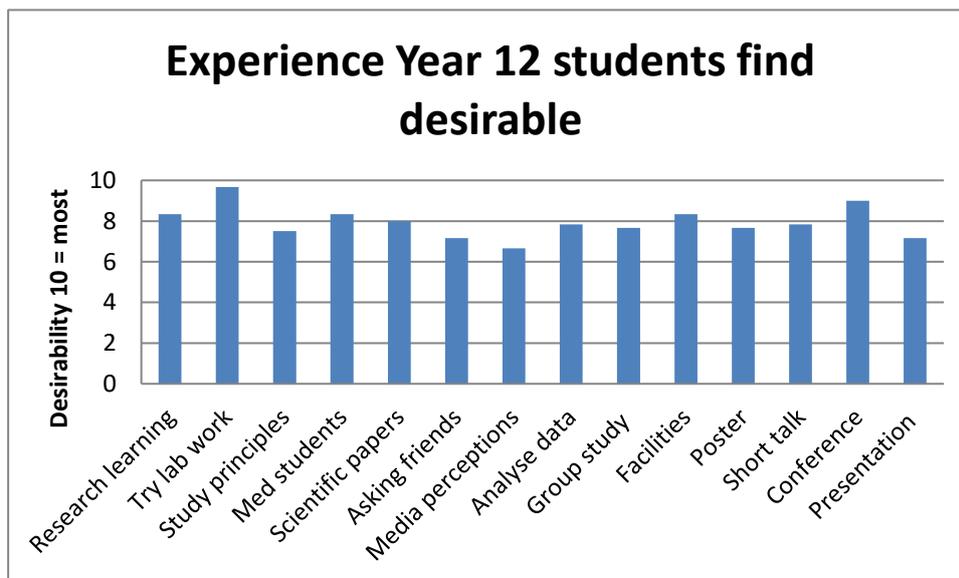
	2019												2020						2021					
	April	May	June	July	August	September	October	November	December	January	February	March	April	May	June	July	August	September	October	November	December	January	February	March
Project timelines	Project starts																Disseminate health fliers	ESID conference	Pop up shop tour at UHB hospitals					
	Recruit Public engagement officer and Post Doc															Develop myth busting material		Myth busting posters / props	Birmingham Library presentation				Analyse impact	
			Baseline setting patient survey															Immune health day					Plan future work	
	Develop website	Disseminate progress through website and social media																Optimise media exposure						
	Meet with PIDUK and IPOPI		Collate patient testimonials														Recruit patients for 'pill box patient' talks	Present patient material						Project end
ESID 2020 project	Meet with ESID LOC - bi monthly														Develop physical props	Plan soap box science t		Pop up shop delivery	Collate and analyse quizz data					
		Develop quizzes			Trial quizz in GP surgery for baseline data													Trial quizz in ICC/library	Quizz launch					
Schools project	Develop invite for schools						Recruit and train medical student mentors												Student attendance at ESID					
														Develop materials for research taster	Reasearch taster event				Schools gala event					
										Recruit students							Produce schools posters	Present posters	Disseminate post event questionnaires to students					
GP project	Recruit GPs		Interview GPs		Develop GP / patient engagement material			Pilot GP engagement material				Apply for RCGP CPD			Roll out engagement material			GP attendance at ESID	Survey impact of GP material				Analyse GP material	

Key Findings from Student Focus Group

We undertook a 90 minute focus group with 6 Year 12 students from across Birmingham and the West Midlands on 4th September 2018. All were hoping to apply to study Medicine and had heard of Immunology. When asked out of 10 how confident students were in describing Immunology as a subject they averaged 5.8/10 with 10 being most confident. They felt the subject was quite difficult scoring 7.3 on average out of 10 with 10 being the most difficult subject. This triangulates with previously published work.

Students were keen to gain a wide spectrum of experience; trying laboratory work, being mentored by medical students, attending the University campus and the ESID 2020 conference more considered most desirable (figure 1). Overall they felt the project offered a very valuable experience (8.7/10) and 100% of students felt they had learned something from the focus group and were more aware about Immunology.

Figure 1



Following the focus group, the project expanded the laboratory element of the project and optimised the medical student contribution. The timing of the project was proposed to interrupt least with school commitments. This work also highlighted the extra considerations that need to be made for widening participation students such as organising or paying for transport and careful balancing of timings to avoid overlap with other commitments such as part-time jobs. All of the students also commented that they felt that this project represented an extremely valuable and unique opportunity compared to other opportunities they were aware of because of the autonomy given to do their own research and frame their own questions.

References

1. [Shillitoe et al, The United Kingdom Primary Immune Deficiency \(UKPID\) registry 2012 to 2017. Clin Exp. Immunol \(2018\)](#)
2. [Wood, P. Primary antibody deficiencies: recognition, clinical diagnosis and referral of patients. Clinical Medicine. 2009; 9\(6\);595-599.](#)
3. Collated data from [digital.nhs.uk](#), accessed on 11th September 2018
4. Data from the [Association of Leading Visitor Attractions](#), accessed on 11th September 2018
5. [Chinen, J et al. 2009 The Journal of Allergy and Clinical Immunology 125 S195-S203](#)
6. [McCusker and Warrington, 2011, Allergy, Asthma & Clinical Immunology 7 S11](#)