



*National Institute for
Health Research*

Improving Patient Care through Research

Nottingham Digestive Diseases
Biomedical Research Unit (NDDBRU)



Contents

- What can you tell me about the National Institute for Health Research (NIHR) Nottingham Digestive Diseases Biomedical Research Unit? (pages 1 & 2)
- How much do you know about your gut and liver? (page 3)
- Would you like to help in clinical research? (page 3)
- What do we mean by Patient & Public Involvement (PPI) in Research? (page 4)
- Why we want YOU to be involved (page 5)
- What's in it for ME? (page 5)
- What time is involved? (page 5)
- Patient's perspectives (page 6)
- Participating in a clinical trial—Mary's story (pages 6)
- The Research Journey and Timeline (pages 7 & 8)
- How can I join the NIHR Nottingham Digestive Diseases BRU - Patient Advisory Group? (page 9)
- How can I find out more about PPI/E? (page 9)
- Your safety FIRST (page 9)
- Confidentiality assured (page 9)
- Your Notes (page 10)

To fill out and send back

REGISTER:

Public and Patient Involvement with the NIHR Nottingham Digestive Diseases Biomedical Research Unit with reversible stamped addressed card



What can you tell me about the National Institute for Health Research (NIHR) Nottingham Digestive Diseases Biomedical Research Unit?

The NIHR Nottingham Digestive Diseases Biomedical Research Unit (BRU) has a mission to take the most promising basic biomedical research breakthroughs and translate them into patient benefit. We focus on the first stages of introducing new treatments, new tests and clinical management strategies to volunteer patients and also using blood and tissue samples from patients to perform clinically-relevant basic biomedical research.

The NIHR Nottingham Digestive Diseases BRU is keen to ensure that meaningful and active involvement of its patients, carers and the wider public is central to achieving excellence in research.

The NIHR Nottingham Digestive Diseases BRU also:

- Supports over 200 people signed up to the Patient Information database;
- Supports the NIHR Nottingham Digestive Diseases BRU Patient Advisory Group (PAG) which is at the centre of **patient & public involvement & engagement** (PPI/E). The PAG currently has 25 members;
- Manages a dedicated web-site with a specific page for PPI/E activities, plus opportunities for YOU to submit your comments and talk about your experiences.

Many of our patients are voluntary participants in research-based clinical trials. Others became involved in different ways, for example through PPI/E - more of that later.



Antonella Ghezzi, Nurse Manager (right), and Mary Ellis (PAG Member, left)

The NIHR Nottingham Digestive Diseases BRU provides:

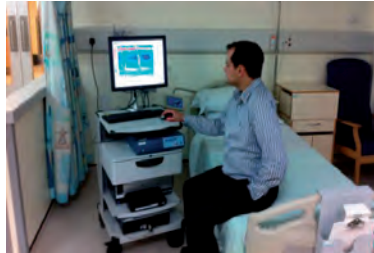
- A central facility for patient based translational research¹
- A staff team dedicated to patient based translational research
- A highly trained group of skilled Research Nurses, and Technicians dealing with tissue and blood samples
- Administrative and Secretarial staff, Clinical Trials Experts, Research Facilitators and a Database Manager
- A register of volunteer patients with specific diseases
- Collections of blood, tissue and pathogens for translational research

¹ Translational research is scientific research that facilitates the translation of findings from basic science to practical applications that enhance human health and well-being.



Our research concentrates on the themes of infections and post-infectious consequences in the GI tract and liver. Some specific areas include:

- Clostridium difficile infections;
- Surgical and wound infections, including MRSA
- Hepatitis C virus infection and its complications including liver cirrhosis
- Helicobacter pylori infection and peptic ulceration
- Gastric cancer
- Other GI infections including Campylobacter jejuni
- Irritable Bowel Syndrome
- Diverticular Disease
- Colonic inflammation and polyposis.



Lucianno Carneiro, Research Fellow

As well as Clinical Researchers in the School of Clinical Sciences, the team of the NIHR Nottingham Digestive Diseases BRU includes some of the best researchers in the nationally first-rated School of Pharmacy and the Sir Peter Mansfield MRI Imaging Centre. Further, the NIHR Nottingham digestive Diseases BRU hosts many Microbiologists and Virologists from the School of Molecular Medicine and The School of Biosciences.



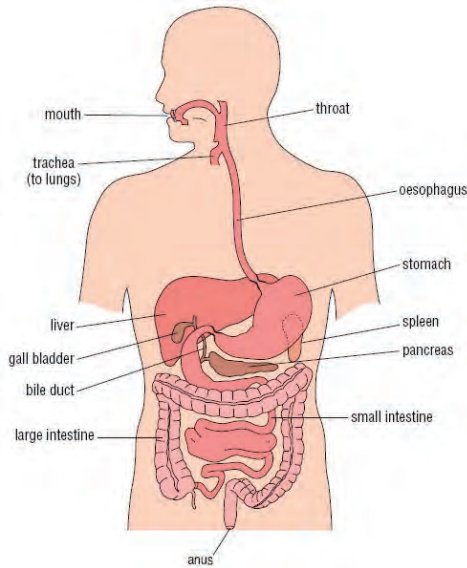
**Andy Wragg,
Patient & Public Involvement and
Engagement Facilitator**



**Antonella Ghezzi
Nurse Manager**



How much do you know about your gut and liver?



As the picture shows food is transferred from the mouth down the oesophagus to the stomach. There it is prepared for digestion, first by being sterilised by acid and then being squeezed by contractions which mix and break-down food to a homogenous liquid. This then enters the small intestine where it is mixed with digestive enzymes including those from the pancreas and bile salts from the liver which allow digestion of fat, protein and carbohydrate to small molecules which can then be absorbed by the small bowel and used by the body.

The colon (large bowel) contains many bacteria which break down parts of the diet we cannot digest and produces some useful food but also some toxins. The liver performs many important functions including breaking down potential toxins from both diet and bacteria in the colon. The last part of the colon absorbs water and nourishment from the colonic contents, the unwanted waste is then stored in the rectum until it is finally expelled via the anus.

Would you like to help in clinical research?

Clinical Research is important, as it helps us to understand how to diagnose, treat, control or prevent health problems. It helps us to increase understanding about health and to improve patient care. Patients are crucial to the research that we undertake, which is performed to the highest ethical standards (see page 9 - Your Safety First).

We therefore rely on the good will and selflessness of patients to participate in our clinical trials to help others with similar diseases.

We feel it is important to the success of the NIHR Nottingham Digestive Diseases BRU to have high level patient input, and our **Patient Advisory Group (PAG)** was created to facilitate **'patient and public involvement'** in our research work.

"I find as a member of the Patient Advisory Group, and knowing the people and procedures involved, this seems to take away the apprehension I would usually have when receiving new treatments" - **Jeff Bloor**



What do we mean by Patient & Public Involvement (PPI) in Research

We refer to Patient and Public Involvement (PPI) when patients and the public are actively and meaningfully involved in Nottingham University Hospitals (NUH) research projects. Researchers and healthcare professionals work **together with** patients and the public to carry out and improve health research to benefit patients and the public. Being involved means that you can support, promote and influence research and you can help to ensure that research information is easy to access and understand.



Roger O'Shea (left) PAG Member and
Dr. Neil Guha (right) PAG Chair

"Being part of the PAG makes you feel you are making a valuable contribution as a patient, to developments within the health service. It also means you get to meet other people with similar interests in medical research." - Wendy Pratt

Examples of Patient and Public Involvement include:

- Helping to identify research that is important and relevant; this can help to ensure that money and resources are not wasted
- Helping researchers to ask the right questions in the best way, as people who use services are best placed to recognise the issues that are important to patients and the public; they can also help to improve the experiences of research participants
- Helping researchers to design and/or carry out their research studies, to help make research more effective
- Helping to improve understanding of all aspects of the patient's treatment and realistic ways to recruit patients to studies; patients and the public might be able to identify possible barriers to recruitment
- Helping to develop accessible information, so that it is easy to find and understand
- Joining a Patient and Public Involvement (PPI) Advisory or Steering Group, to offer a patient/public perspective on research and associated activities
- Helping to **interpret** research results; patients and the public can advise on areas of interest to be featured in reports, or analysed further
- **Advising** where there are problems with a particular trial or other well designed study
- Helping to **develop** guidance and briefing documents and training programmes, to make sure that they are appropriate and easy to understand.



Why we want YOU to be involved

We believe that PPI is fundamental in ensuring that your views continue to influence the delivery of exceptional research-led healthcare now and in the future.

You do not need any research experience, as a patient you are the expert. It is from your experiences that we learn and grow as a research body, keeping us realistic and in touch with our patients and our communities.

Patients and other members of the public can bring a different perspective that is not always the same as those of researchers. Your involvement helps to make certain that the entire process is focused on what is important to people and therefore more relevant and acceptable to the people who need to use our services.

What's in it for ME?

People with personal experience of healthcare, or a carer of someone with health issues, are the ones who are best placed to comment on what research is needed and how that research should be done.

Being part of our **NIHR Nottingham Digestive Diseases BRU Patient Advisory Group** means you will be able to partake in numerous activities:

- Comment on our researchers treatment ideas
- Comment on how that research treatment will be carried out
- Reading and giving a lay review on patient information sheets, consent forms, patient questionnaires etc
- Support the recruitment process by providing passive support for first-time participants in clinical trails (our new '**buddy scheme**');
- Provide advice on the development of information leaflets and posters,
- Supporting the ongoing update of our website, write features in newsletters.

Getting involved will give you a say in research. You will help us to decide on which research we should prioritise which aim to develop better treatments and improved services. You will gain a better understanding of how the NHS works.

You will meet new people (researchers, other patients and members from the community). Most of all, it enables you to make a valuable contribution to health research.

What time is involved?

You can be involved in as many or as few meetings or activities as you wish depending upon your personal circumstances. Much of this work can be done via email or by post. The Patient Advisory Group oversees a number of 'focus groups', who will meet as often as is necessary to do the work shown in the activities above.



patient's perspectives

"Being involved in PPI makes you feel like one of the team and is not only interesting but rewarding also" - **David Harrison**

"By participating, as a healthy volunteer, in several clinical trials I feel that I am making a small contribution to all the Research on-going in the BRU" - **Member of the PAG**

"Generally, we as patients can sometimes feel left out of the loop when it comes to making medical decisions about ourselves or others, so it is nice to feel part of the decision-making process and that's what membership of the BRU PAG means to me. Getting a chance to read about upcoming medical research, in areas which may have some impact on our lives, and give the patient/ participant perspective is empowering and enriching" - **David Hird**

Participating in a clinical trial – Mary's story

"I think the benefits patients take out of attending a clinical trial are probably far better than attending a regular clinic like I do. I attend the liver clinic every six months for basic check up but when I'm on the clinical trial I get the "Full Monty", really everything, so it puts my mind at ease.

Leading up to the clinical trial I was attending the liver clinic at the treatment centre at QMC and I think they just thought that I was a good candidate for it and I was happy to do it. When I first took part in a clinical trial I was very nervous because I'd not done anything like that before.

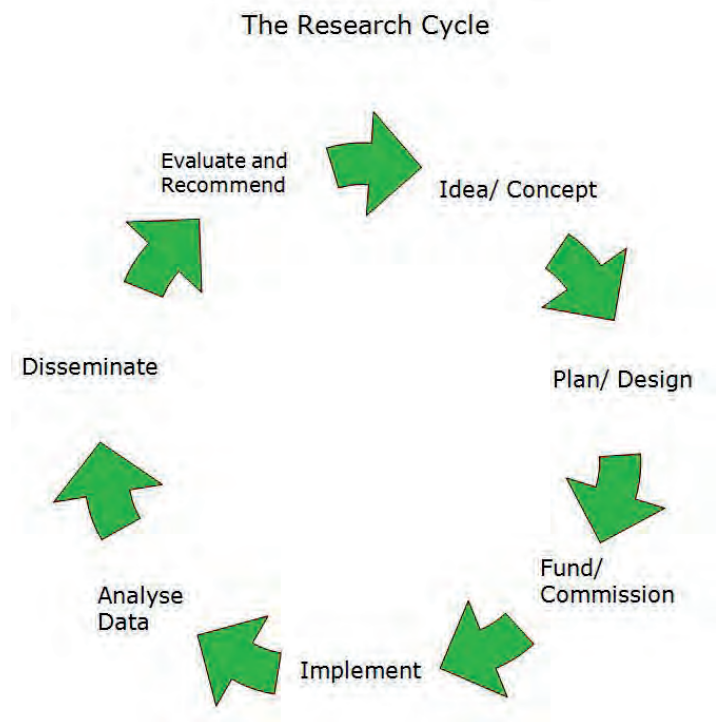
As a patient in the clinical trial I was injected with green dye to see how fast it progressed to my liver to see how my liver was working. I was given an ECG, blood pressure, blood tests. Didn't find it difficult to participate in a clinical trial with the medical aspect but I had to do some memory tests, drawing on paper with numbers and things like that and it was more scary than an exam but the medical part was fine.

The care and support that I received during the clinical trial was brilliant, everybody was so nice to me and put me at ease. The work that's done in the Biomedical unit is brilliant because it all goes towards helping others now and in the future.

The best thing I can say I think about my participation in the trial is the people, they've all been wonderful, they're all friendly, all very reassuring and put your mind at ease. They won't ask you to do something that you're not happy to do. I would say to any patient that's pondering about entering into a clinical trial 'Do it. Go for it', y'know there's nothing to be scared of."



The Research Journey and Timeline



(i) IDEA/CONCEPT - What should be researched? What topics can be identified? Which of these are most important?

Ideas can come from many areas such as, new advances in technologies, increases in scientific knowledge, clinical practice, **patient/public groups**, National focus groups, Patients/service users or previous research.

(ii) PLAN/DESIGN - This is the **'how to'** stage, which is the best way to carry out the research study to ensure that the results are accurate. Plan the next steps that will ensure that the research question being asked can be answered. Use methods that ensure that the project is practical and manageable.

Planning and design are influenced by many factors: the topic being studied, the funding stream being applied for, budget restrictions, ethical considerations (those that may lead to the study not being granted ethics approval) and the type of data that will be collected/used.



(iii) FUND/COMMISSION – When submitting an application for funding researchers need to request funds to cover the cost of running a research study. There are a number of different funding bodies in the UK that researchers can apply to including government funded organisations such as the National Institute for Health Research and charities. Each funding stream has a different focus, some cover a specific topic while others have a specific purpose such as service improvement. The funding application stage can be influenced by the quality of the proposals being submitted (for example some proposals are good ideas but have not been well designed). Not all research study applications are successful.

(iv) IMPLEMENT - This is the ‘**doing**’ part of the research cycle where the study is carried out. Ethics approval must be sought and gained prior to starting a research study. To help recruit patients to the study the researchers will usually be supported by the NIHR Clinical Research Network. The study is managed by a project management team and the project steering group, and they decide how the study should proceed on a day to day basis. The environment in which the study is being carried out, changes in policy and practice can also affect the study.

(v) ANALYSE DATA - Analysis can identify trends and themes from the data (what we found out from the study). The most commonly used form of analysis is statistical analysis. Interpretation of the data is to find the meaning of the trends and themes identified (how did participants in the study respond to the treatment). There are numerous influences on analysis and interpretation such as the outcomes being measured in the project (was the treatment outcome effective) and the method being used: quantitative (how many participants responded positively or negatively to the treatment) or qualitative (in what ways).

(vi) DISSEMINATE - The results of the project are shared with interested parties. The research findings are usually written up as a research paper and published in medical, academic and professional journals. Moreover, the National Institute for Health Research requires that research papers are deposited with Europe PubMed Central - <http://europepmc.org/> - which offers free access to research articles. Research findings are also disseminated through local and national press, patient representative organisations, health charities, as well as at conferences and events.

(vii) EVALUATE AND RECOMMEND - Assess in hindsight what worked, what didn't work and why. Recommendations for further studies can be made. This may feed into a bigger study. Many projects are broken down into a number of stages to make them manageable and so recommendations would directly feed into the planning and designing of the next stage.

Patient & Public Involvement is fundamental in ALL of the above stages of the Research Cycle.



How can I join the NIHR Nottingham Digestive Diseases BRU Patient Advisory Group?

There are a number of ways you can join the group. You can register your interest by filling out our 'contact form' - see below/also available on our new website – www.nddcbru.org.uk

Alternatively, you can contact, Andy Wragg, Patient & Public Involvement and Engagement Facilitator: Tel: 0115 924 9924 ext 64429; Email Address: andrew.wragg@nuh.nhs.uk

How can I find out more about PPI/E?

Visit the NIHR INVOLVE² web-site, which supports greater public involvement/engagement in NHS, public health and social care research www.invo.org.uk/find-out-more/what-is-public-involvement-in-research/

Visit National Institute for Health Research (NIHR)
www.nihr.ac.uk

Your Safety FIRST

Large numbers of people take part in thousands of clinical research studies and trials in the UK every year. All clinical research undertaken at Nottingham University Hospitals NHS Trust is reviewed and approved by an independent NHS Research Ethics Committee and by the Trust before it can start. This ensures the rights, dignity, safety and well-being of trial participants are protected. Each study is designed to keep risk to a minimum. Participants in every study are monitored carefully throughout and their safety and wellbeing always comes first. Equally, as a member of our Patient Advisory Group, your details and any disclosed information concerning your health (past and current) is kept secure under our confidentiality procedures.

Confidentiality assured

If you wish to become a member of our Patient Advisory Group and/or take part in a clinical trial or study, all information collected about you will remain strictly confidential. The results of studies you'll be supporting (or participating in) are usually presented to large medical meetings and published in medical journals to ensure others can use the results to improve health care. You will not be identified in any report or publication unless you specifically wish to as a PPI/E advocate.

² INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.



Your Notes

REGISTER

Public and Patient Involvement with the NIHR Nottingham Digestive Diseases Biomedical Research Unit

Name.....

.....

Address.....

.....

..... Post Code.....

Telephone Number: Landline.....

Mobile.....

Email Address:.....

What type of digestive diseases or liver condition do you have (if any)?

.....

Any other information or interests.....

Are there areas of Patient and Public Involvement (PPI) work you're interested in? The Patient Advisory Group oversees a range of focus groups in following areas, **please tick** as appropriate.

<input type="checkbox"/>	Commenting on and developing information documents , e.g. leaflets, posters and reports etc.
<input type="checkbox"/>	Informing people what is happening in research by developing different ways of communicating this e.g. via the BRU website, newsletter, video etc
<input type="checkbox"/>	Developing ways to support participants who are thinking of taking part in clinical trials/studies (via a Buddy Scheme) e.g. supporting recruitment , helping them provide their consent, providing reassurance etc.
<input type="checkbox"/>	Giving comments and opinions on research and related activities e.g. providing a lay review on patient information sheets, providing information that assists researchers in the design of a study, distribution of research results etc.
<input type="checkbox"/>	Supporting and identifying research design priorities by disease area i.e. gastro, liver related diseases

Please note that we will do our best to accommodate your preferences, but it may not always be possible.

Are you happy for your contact details and PPI interests above being kept in a database so we may contact you in the future? Please tick either YES or NO)?	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>

We are recruiting 'healthy' volunteers to participate in **Clinical Research Trials (CRTs)**. If you are interested, and would like to have your contact details on this database, please tick this box. For further information on CRTs visit our website - www.nddcbru.org.uk

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Your Team



- | | | |
|---|---|---|
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| 2 Emma Bradley, PAG Administrator | 10 Suzanne Henry, Research Nurse | 18 Dr. Grace Dolman |
| 3 Dr Nav Palaniyappan | 11 Dr. Jonathon White | 19 Professor Robin Spiller |
| 4 Louise James, Clinical Support Worker | 12 Andrew Wragg, PPI/E Facilitator | 20 Samantha Warburton, Clinical Support Worker |
| 5 Professor Guru Aithal | 13 Maggie Nicholls, Research Nurse | 21 Dr. Mark Fox |
| 6 Denise Norris, Clinical Support Worker | 14 Antonella Ghezzi, Nurse Manager | |
| 7 Dr. David Harman | 15 Dr. Krishnar Ragunath | |
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This document can be accessed in different languages and formats.

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