

Nottingham Digestive Diseases Biomedical Research Unit PATIENT ADVISORY GROUP (PAG)



HEADLINE STORY—Liver Disease

Why targeting liver disease is so important for all of us - See Pages 1 & 2

Patient & Public Involvement (PPI)

What is **patient and public involvement** and why it sits at the heart of clinical research - Page 3

Want to know more about joining the Patient Advisory Group – PAG?

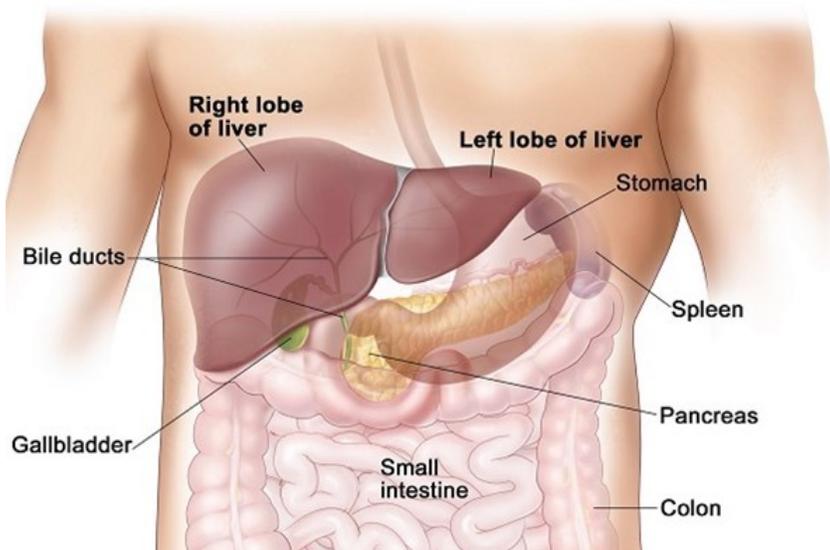
Contact details and how to join the PAG: a dynamic and growing band of patients (current and former) and members of the public who have a passionate interest in digestive diseases - See Page 4

Why targeting liver disease is one of the top health concerns in the UK

Liver disease is a growing health burden and is currently the third leading cause of premature death in the UK with the death rate continuing to rise. This is despite the fact that the **majority** of liver disease results from lifestyle related risk factors including excess alcohol use, obesity (and related type 2 diabetes) and intravenous drug use. However, many cases of liver disease remain undetected as most people do not have symptoms until the late stages of liver disease.



PAG members at work.....



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Why are we not identifying liver disease earlier?

In primary care, we rely upon liver function tests (blood test) (LFTs) to detect patients requiring further investigation for possible liver disease. This is an inadequate approach; LFTs are woeful at detecting liver disease before patients have symptoms. Subsequently in the UK, 50% of patients with cirrhosis are diagnosed for the first time when hospitalised with symptoms of liver failure resulting in a reduced quality of life and an increased risk of death and associated healthcare cost. In contrast, many patients with abnormal LFTs do not have liver disease, resulting in anxiety for patients who undergo unnecessary invasive investigations.

There are newer non-invasive tests which detect liver disease more accurately than traditional blood tests, and importantly avoid the need for invasive investigations. However, at present these new tests are not widely used within the community to identify liver disease.

What is this new non-invasive test?

Fibroscan™ is a piece of medical equipment which measures liver stiffness, and can detect earlier stages of liver disease before patients develop symptoms. We have piloted an investigation pathway using a simple blood test and a Fibroscan in the community (usually your local GP practice) as part of a collaboration between the Nottingham Digestive Diseases Biomedical Research Unit and East Midlands Academic Health Science Network.

Importantly, 72% of the patients with an abnormal Fibroscan, and 91% of patients diagnosed with cirrhosis in the pathway, had normal LFTs and would not have been detected through standard care. Feedback from the patients participating in the pathway was very positive. More than 90% of patients stating that they would definitely recommend the service to their family and friends.



95% of investigations were performed in the community setting, and 95% attended their community fibroscan appointment. See Fig 1 below

IN A COMMUNITY POPULATION OF 20,368 PATIENTS, THE SCARRED LIVER FOUND

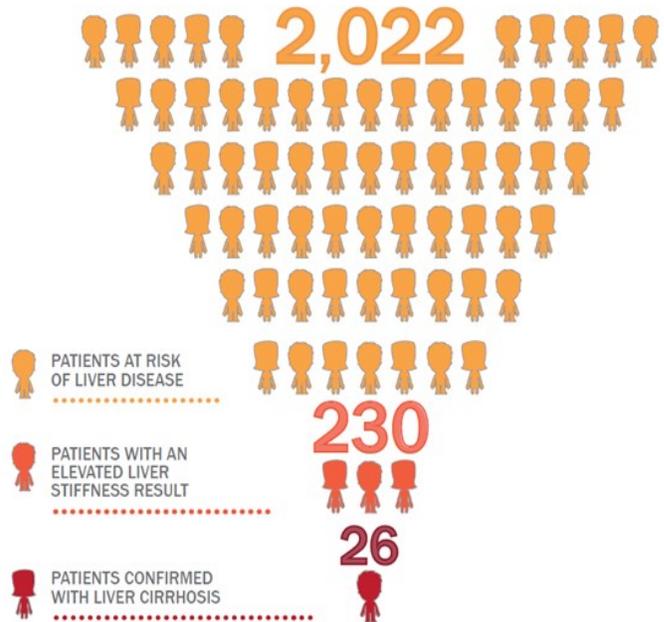


FIG 1: The 'Scarred Liver' is the name given to an Exhibit displayed at The Royal Society Summer Science Exhibition in 2013. The exhibit demonstrated the science behind, and the patient & public endorsement, for the community based liver service detailed on this page.

What next?

The future challenge is to implement the community based liver-service into multiple GP practices in Nottingham. With earlier and more accurate identification of liver disease a targeted approach to manage patients' lifestyle related risk factors could be implemented resulting in reduced progression of liver disease, and consequently a reduction in liver-related deaths and healthcare costs. Our goal is to work with GPs, patients and clinical commissioning groups (CCGs) to raise both the profile of liver disease and improve the diagnosis and management of this condition. The PAG is working alongside our research team to help us achieve this goal.

Any questions? Visit nddcbru@nottingham.ac.uk and type in 'Community Fibroscan' as your email heading and we will get back to you as soon as possible.

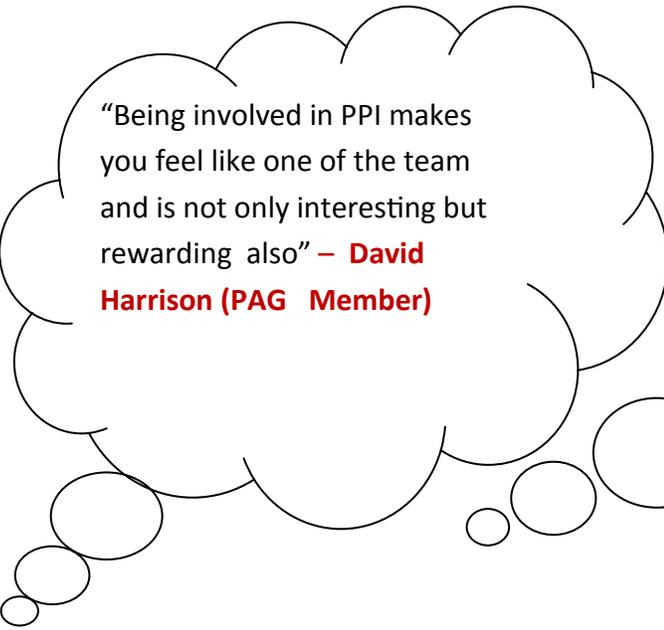
Patient & Public Involvement (PPI)

We refer to Patient and Public Involvement (PPI) when patients and the public are actively and meaningfully involved in research projects. Researchers and other healthcare professionals work **WITH** patients and the public to carry out and improve health research to benefit patients and the public in the long-term. Further, being involved means that you can support, promote and influence research and help ensure that research information is easy to access and understand.

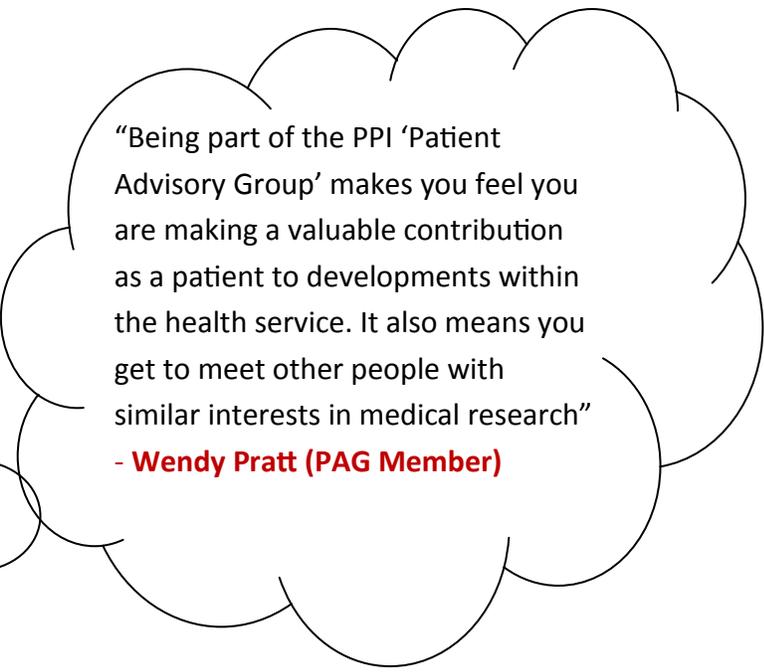
PPI is managed and delivered through the Patient Advisory Group (PAG). The main article in this newsletter (community based liver service) was developed alongside the PAG e.g. consultations on the benefits of delivering the service within GP surgeries, video stories for the Royal Society Science Exhibition in 2013 to more recently supporting approaches to Clinical Commissioning Groups to implement the community based liver-service into multiple GP practices in Nottingham.

Other examples of Patient and Public Involvement work includes:

- ◆ Comment on researchers treatment ideas and how it is carried out;
- ◆ Reading and providing a lay assessment on clinical trial documentation e.g. patient information sheets, consent forms, questionnaires etc.;
- ◆ Support the recruitment process by providing passive support for first-time participants in clinical trials (our new **Study Advocacy Volunteers**);
- ◆ Provide advice on the development of information leaflets, posters etc.;
- ◆ Join our 50 strong Patient Advisory Group and become an active member striving to put PPI at the forefront of clinical research;
- ◆ Support the ongoing update of our website, write features in this newsletter...and much more.



“Being involved in PPI makes you feel like one of the team and is not only interesting but rewarding also” – **David Harrison (PAG Member)**



“Being part of the PPI ‘Patient Advisory Group’ 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 (PAG Member)**

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.

It is not uncommon for patients who've previously participated in a clinical trial to enquire about helping research development in the future. Whilst as a patient you are able to bring an element of expertise with you, you can still support our work without any research experience at all. We have a number of healthy volunteers in our ranks too. It is from your diverse experiences that we learn and grow as a research and patient body, keeping us realistic and in touch with the public and our local communities.

Patients and other members of the public bring a different perspective that is not always the same as those of researchers. We have learned this ourselves, and our working relationship with the research team is much closer and respectful as a result. Your involvement helps to make certain that the entire process is focused on what is important to YOU and consequently more relevant and acceptable to those who use our services.

What's in it for ME?

People with personal experiences 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. Page 3 of this newsletter provides a snapshot of the work you could be involved in.

What time is involved?

You can be involved in as many or as few meetings or activities as you wish. Much of the 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 shown on page 3. You will have your travel and parking expenses paid, and on many occasions we will provide you with a meal.

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 'registration form' available via the contact details below. Alternatively, visit our website at www.nddcbru.org.uk

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