

Developing Patient and Public Involvement with Liver Disease Research in an NHS Foundation Trust in Collaboration with the NIHR Birmingham Liver Biomedical Research Unit (BRU)

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ABSTRACT

- Liver disease is now the fifth commonest cause of death in the United Kingdom (BASL & BSG 2009) and it is associated with significant morbidity
- Research into liver disease needs to incorporate education, raising awareness, prevention, detection, intervention and management into its strategic plans
- Public and Patient Involvement (PPI) in research helps optimise delivery in research studies and clinical trials

Definition of our Patient and Public Involvement Panel:

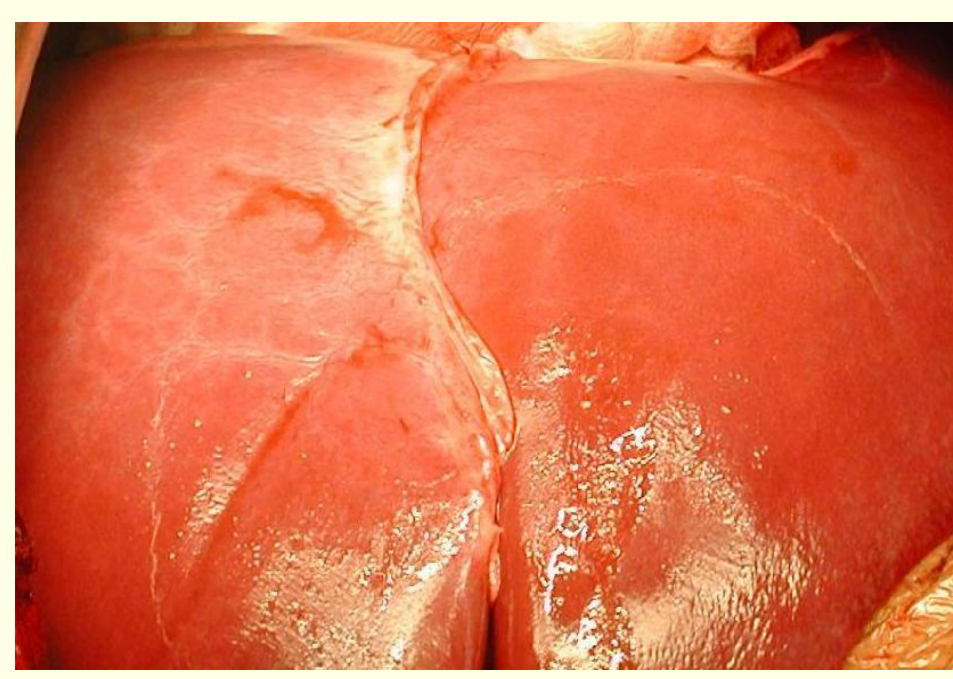
A group of volunteers who may be patients, ex patients, or those with a general interest in liver disease, who meet several times a year with the intention of contributing to research, increasing their knowledge of liver disease and actively promoting awareness of liver health.

Definition as agreed by the NIHR Birmingham Liver BRU PPI Panel

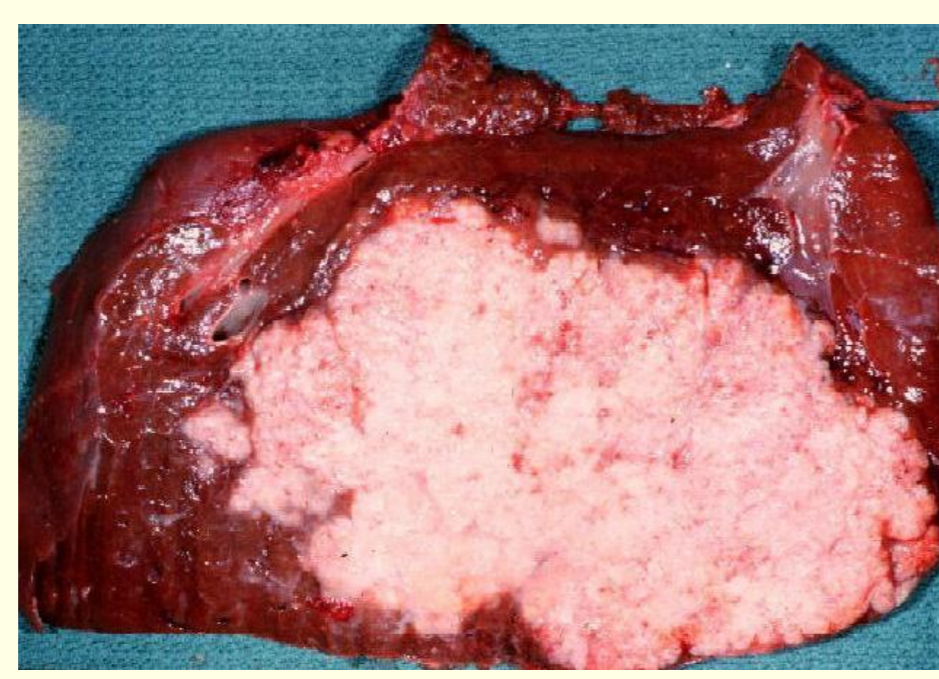
THE LIVER

- The liver is the second largest organ in the body
- It filters over a litre of blood a minute removing toxins which have entered the bloodstream by eating, drinking and breathing

It is an essential organ – humans cannot survive without a liver



A healthy liver



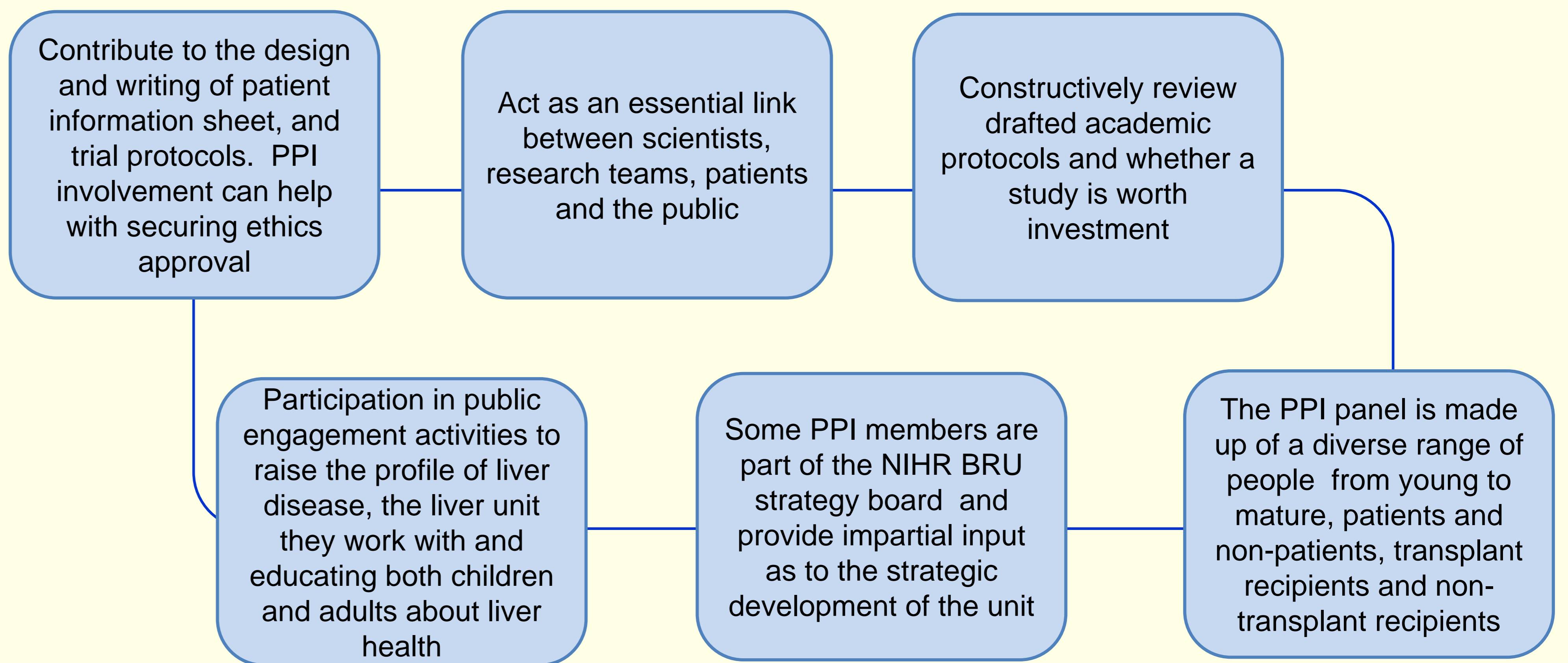
An unhealthy liver

LIVER DISEASE RESEARCH

- Clinical trials are research studies looking at possible **new drugs, treatments and medical devices**
- There are various phases which must be completed, each of which involves an increasing number of volunteer patients
- Clinical trials also look at medical interventions, such as screening, diagnosis and procedures

The ethics of a study are very important (how relevant it is and whether it fully considers a patients needs). No clinical trial can start without obtaining ethical approval from an ethics committee

HOW A PATIENT AND PUBLIC INVOLVEMENT PANEL CAN AFFECT RESEARCH AND TRIALS



Alan Hyde, transplant recipient and PPI member, helping out at a Meet the Liver Scientist Day



Graham Bunch, PPI volunteer assisting with a public engagement event at Birmingham's Think Tank with the team



Some of the NIHR Birmingham Liver BRU PPI panel. Not everyone was available when this photo was taken

SETTING UP A PPI PANEL

HOW DID WE GET STARTED:

- Attending NIHR and INVOLVE workshops on PPI
- Joined the PPI forum of the Birmingham and Black Country NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC)
- Production of a leaflet showing why we need a PPI panel
- Distribution of leaflets and advertising for PPI members via GP surgeries, liver support groups, hospitals, clinics etc
- Posters and letters sent to everyone who expressed an interest in the PPI panel, inviting them to attend an education day
- Advertising for the education day via internal NHS and University websites
- Education day took place, chaired by a member of CLAHRC, showing:

The need to involve PPI with research

How and why this was necessary

What ongoing teaching and educational support was offered

- Everyone who attended the education day 'signed up' to become a PPI panel member. They were subsequently CRB checked and attended a half day induction event within the Trust

The panel has been successfully established since April 2011

The panel are extremely keen and motivated on educating both adults and children on the importance of liver health and the dangers of obesity, alcohol and drugs, and how these can damage the liver

Acknowledgements

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HOW HAS THE PPI PANEL HELPED

SINCE ITS INCEPTION, THE PPI PANEL HAS:

- Reviewed and provided constructive comments on information sheets. The input into one patient information sheet helped achieve ethics approval and the PPI involvement was commended by the ethics committee
- Helped establish Liver FOCUS, a bi-annual educational newsletter distributed to support groups, GP surgeries, clinics, patients, NHS waiting areas. A PDF version is also online
- Actively submitted articles for Liver FOCUS, suggested items for inclusion and edited the newsletter
- Assisted with numerous public engagement events including those at the Queen Elizabeth Hospital and Birmingham's Thinktank science museum (where over 1500 children attended)
- Liaised with scientists, doctors and researchers regarding planned clinical trials and their value
- Suggested ideas for public engagement events and awareness activities
- Attended educational workshops, listening to updates on the latest research and finding out more about the various forms of liver disease. Following these talks, PPI members provide feedback and give a perspective that many scientists, doctors and researchers have not considered

GETTING INVOLVED

Should you wish to become actively involved in helping to shape the future of liver studies and increase your knowledge of liver disease, please volunteer to be part of our Patient and Public Involvement Panel. You only need to spare a couple of afternoons per year (some reimbursement for parking and mileage can be given) and provide your feedback on patient information sheets as and when they are sent to you.

No medical or specialist knowledge is required, just a genuine interest in liver disease and helping others.

Email: LiverResearch@contacts.bham.ac.uk Web: www.birmingham.ac.uk/clr-ppi