

## Patient and Public Involvement and Engagement Strategy for the Surgical MedTech Co-operative

2018 - 2022





### Introduction

This strategy sets out our vision, commitment and approach to public and patient involvement (PPI) and engagement (PPE) in research. It underpins the NIHR Surgical MedTech Co-operative's commitment to embed patient experience into medical technology research.

The NIHR Surgical MedTech Co-operative (MIC) supports the development of new technologies in the fields of colorectal, vascular and liver, pancreas and gall bladder (hepatopancreaticobiliary/HPB) surgery, improving both healthcare and quality of life for patients. Through our nationwide network of clinicians, engineers, scientists, industry and patients, we identify new areas in need of innovation, support research to address these clinical problems, and provide a resource for evaluating new surgical technologies within the NHS, helping them to move into clinical practice.

The objectives of the Surgical MIC are to:

- Develop research collaborations
- Fund relevant pilot/proof-of-concept studies to support larger-scale research projects, device development, health economics and care pathways
- Leverage additional funding to undertake full-scale studies

Ensuring that patients and the wider public are involved in these activities undertaken within the Surgical MIC is a key priority for us. Patients and the public bring a wealth of experience and provide valuable perspectives on the way that medical technology is developed.

This strategy has been developed by the NIHR Surgical MIC Management Group and the Surgical MIC Patient and Public Involvement Group. The design and delivery of the Surgical MIC public and patient involvement activity is supported by the Steering Group which also provides advice on patient and public engagement.

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#### Governance

Implementation of this strategy is the responsibility of the Surgical MIC Management Group. A Surgical MIC PPI Committee will be established to act as a critical friend and advisor to the Surgical MIC in the delivery of this strategy.

The role of the PPI Committee is to:

- Provide oversight, input and advice on patient and public involvement activities
- Facilitate a shared understanding of patient and public involvement in research and help to develop consistency across the NIHR Surgical MedTech Cooperative themes.
- Identify, discuss and address issues of common concern and avoid unnecessary duplication of effort.
- Facilitate access to support and resources that are available from INVOLVE and other PPI group member organisations.
- Exchange ideas, strengthen skills and share examples of good practice.



#### **MIC Management and Governance Arrangements**

<sup>\*\*\*</sup> See appendix I for details on leadership

#### Definitions

NIHR define public involvement in research as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them". Examples of public and patient involvement activity include working with researchers to develop or comment on research materials, providing advice as members of a project steering group, and undertaking elements of research e.g. conducting interviews with participants.

NIHR define public engagement as "where information and knowledge about research is provided and disseminated". Examples of public engagement activity include disseminating the findings of a study to research participants, colleagues or members of the public, raising awareness of research through media such as television programmes, newspapers and social media and open days at research centres where members of the public are invited to find out about research.

When using the term "public" we include patients, potential patients, carers, members of the general public and people who use health and social care services. Whilst all of us are actual, former or potential users of health and social care services, an important distinction needs to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.



#### **Our Vision**

Our vision is to achieve meaningful public and patient involvement and engagement in the planning, prioritisation and communication of surgical research and have an impact in the clinical adoption of surgical technology.

The overarching principle behind these suggestions is that: "at every level where clinicians have influence, we ensure patients do too."

#### **Goals and Objectives**

## Goal 1. Involve patients and the public in our governance and leadership so that our decisions reflect and consider the public interest.

Patients and the public need to have shared decision making to truly make their contribution integral to the Surgical MIC core business. This promotes accountability and transparency in our work, and it also contributes to the prioritisation of activities that increase identifiable improvements in patient health outcomes and patient experience. We will:

- Set up the Surgical MIC PPI Committee with representation from colorectal, HPB and vascular groups to provide oversight, input and advice to the Surgical MIC Management Group on PPI/E activities.
- Have PPI representation on our Surgical MIC Management Group to review the portfolio of technologies and develop the MIC's schedule of PPI/E activities.
- Have PPI representation on our joint partnership board with the Leeds Teaching Hospitals NHS Trust and the University of Leeds.

## Goal 2. Work in collaboration with key research charities and the Surgical MIC PPI Group to co-produce research and activities.

To promote co-production for developing new surgical medical technology concepts, we will:

- Identify opportunities for joint-funding and collaborations to encourage and support PPI/E activity and input.
- Involve the Surgical MIC PPI Group when developing proof-of-concept funding calls and reviewing subsequent applications.
- Promote continuous involvement of PPI/E by ensuring the patients' expertise informs the project from the earliest design stage.

## Goal 3. Increase our capability and capacity to deliver PPI/E across the Surgical MIC and to industry.

We would like to include a development pathway for our MIC PPI Group to aid retention of members and the generation of ideas outside of formal meetings. We will:

- Provide an online forum to facilitate recruitment of members to our PPI Group, provide peer support and to encourage interaction with researchers.
- Provide role descriptions to PPI contributors
- Make use of local PPI groups (e.g. LTHT PPI, Leeds Vascular Patient Interest Group, Healthwatch Leeds, Yorkshire Cancer Research, Leeds IBD panel) for project-based focus groups.
- Work with other NIHR infrastructure in Leeds to identify (via survey) support and training needs that help PPI members to be effective in their roles.
- Identify and provide access to appropriate training opportunities for PPI members.
- Identify opportunities for PPI contributors to make informal or social connections with each other as well as formal ones.



• Support industry and researchers to include lay members on MedTech projects.

# Goal 4. Offer involvement opportunities that are accessible, extend demographic and geographic reach, and that reflect research needs.

We believe that involvement in research as lay partners and participation in research should be accessible to everyone and we aim to broaden the diversity of those involved in our PPI/E activities. To this end we will:

- Identify opportunities for working with local partners, third sector organisations and communities (i.e. Healthwatch) to promote and facilitate the inclusion of under-represented and seldom-heard groups.
- Promote opportunities for involvement via the Surgical MIC PPI Group, Surgical MIC website, People in Research and NIHR Innovation Observatory Voice.
- Provide multiple involvement platforms by utilising online, phone, webex, live video, social media and online community forums.
- Offer travel bursaries and expenses for PPI members to attend Surgical MIC and related events.
- Use the Surgical MIC website to promote PPI/E activities across the MIC.

# Goal 5. Collaborate with key players in local and national health research to communicate engagement and involvement activities and opportunities.

We aim to share learning and resources to support effective PPI/E, making best use of resources and reducing duplication. To this end we aim to:

- Work closely with the NIHR Leeds In-Vitro Diagnostics Co-operative (Leeds MIC) and other NIHR infrastructure on maximising our resources and shared processes.
- Investigate how we can make a meaningful contribution to national PPI/E networks, guidelines and standards development, and impact evaluation.

- Take part in science and research exhibitions hosted by our partners and charities. E.g. Be Curious (University of Leeds public engagement event)
- Engage with organisations such as Health Tech Alliance and the Medical Technologies Group, to engage the public in our research.
- Seek out opportunities to write guest blogs and/or articles for charity magazines and other public facing entities.
- Consider the appointment of a PPI/E Communications Lead to enable the implementation of a communication strategy (i.e. Patient Research Ambassadors – to improve research opportunities and communications).

## Goal 6. Embed both standards for public involvement, and also a culture of feedback and evaluation to demonstrate and evidence the impact of PPI/E.

We will take account of appropriate standards in PPI/E and embed a culture of evaluation to demonstrate and evidence the impact of PPI/E. To this end we will:

- Investigate how we wish to define what PPI/E impact means to the Surgical MIC and its PPI Group.
- Set up an internal system to record PPI/E activity and contributions in respect of grant applications funded, patient reported outcome measures (PROMs), PPI-led projects, and case studies
- Develop a PPI/E strategy action plan for the monitoring, reporting and evaluation of PPI/E.
- Disseminate research with the help of our PPI group and PPI/E progress at the Surgical MIC National Meeting and other research/charity conferences and events.



#### **Resources**

The NIHR Surgical MIC is funded by the NIHR and has a modest budget but we will aim to supplement via external funding attached to PPI/E for travel, expenses and pre-grant activity. We will endeavour to make sure that all post-grant PPI/E activities are costed into researcher bids. No PPI member will be left out of pocket as a result of their involvement and costs incurred for involvement will be paid.

The NIHR Surgical MIC follows the INVOLVE Guidelines on payment for PPI work and has a detailed policy on payment and recognition.

## Reporting, Monitoring and Review of the Strategy and Action

#### Plan

We need to be sure that the activities we are involved in have added value. The following mechanisms exist to ensure regular internal and independent monitoring of PPI activity against annual Action Plans, strategic goals, and overall aims:

<u>Management Group meetings</u> – 6 weekly meetings with core team, clinical leads, academic leads and clinical research fellows.

<u>Joint Leeds MIC PPI/E Working Group</u> – this is with NIHR@Leeds infrastructure and will steer and oversee the activity in the supporting action plan, meeting on a quarterly basis. Progress against the strategy will be reported at Steering Group and Management Group meetings.

<u>PPI Committee meetings</u> – meetings are held twice a year with core team, PPI representatives and clinical leads.

<u>Steering Committee meetings</u> – meetings are held twice a year with funding, industry, PPI representatives, in addition to Leeds Teaching Hospitals and University of Leeds representatives, clinical and workstream leads.

<u>NIHR</u> - The Surgical MIC will report the outcomes of this strategy annually to the NIHR / The Department of Health and Social Care (DHSC). Our strategy will be made available on our website.

The action plan and strategy are living documents and will be reviewed by the 30th April each year to reflect lessons learnt through self-assessment and changes in priorities/legislation.

#### Acknowledgements

This strategy has been developed in partnership with NIHR@Leeds infrastructure (*Leeds Biomedical Research Centre, Leeds Clinical Research Facility, NIHR Leeds Invitro Diagnostics Co-operative*) in order to streamline and build upon our activities, efforts and resources. A series of meetings, surveys and focus groups with our patient and public involvement group have greatly informed the content. We would like to thank and acknowledge the following members of the Surgical MIC Patient and Public Involvement Group who have co-produced this strategy: Philip Bell, Leslie Booth, Alan Clarke, Nicola Dames, Annabel Dawson, Jaqui Williams Durkin, Deborah Gilbert, Dex Hannon, Rebecca Harmston, Glyn Hughes, Maureen Naylor, Margaret Ogden, Natalie Toper, Pete Wheatstone.

#### References

- NIHR (2015) Going the extra mile: Improving the nation's health and wellbeing through public involvement in research. <u>https://www.nihr.ac.uk/patients-and-public/documents/Going-theExtra-</u> Mile.pdfHRA
- Involve (2018) Payment and recognition for public involvement. <u>http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/</u>



#### Appendix I – Background to the Surgical MedTech Co-operative

We are one of eleven Medtech and In vitro diagnostics Co-operatives (MICs) funded by the National Institute for Health Research (NIHR) to act as a centres of expertise that focus on clinical areas of high morbidity and unmet need for NHS patients.

The aims of the NIHR Surgical MedTech Co-operative are to:

- To develop new concepts, demonstrate proof of principle and devise research protocols for new medical technologies that are applicable across the NHS.
- Improve the quality of life and effectiveness of healthcare services for patients undergoing colorectal, hepatobiliary (HPB) and vascular surgery.
- Work collaboratively with patients and patient groups, charities, industry, clinicians and academics.

Surgery plays a central role in the management of many medical conditions. It restores function following trauma and disability, palliates chronic disease, and is central to the treatment of many cancers. Around 4.7 million hospital admissions involve surgical care every year in the NHS, on average one every 7 seconds, and account for 11.2 million hospital bed-days. The number of surgical procedures performed each year has risen by 27% over the past decade; a trend that is set to continue as the population ages. General Surgery, including colorectal, vascular, and HPB, accounts for the highest level of activity (1.3 million procedures/year).

#### **Clinical Themes**

The work of the NIHR Surgical MedTech Co-operative focuses on three areas of surgery: colorectal, vascular and hepatopancreatobiliary (HPB), which involves surgery of the liver, gall bladder and pancreas.



Our <u>colorectal theme</u> – led by Professor David Jayne – covers surgery for colorectal cancer and diverticular disease, more common in elderly patients, and for chronic conditions found in younger patients such as inflammatory bowel disease, benign anorectal conditions and pelvic floor disorders.

**Areas of expertise:** nanotechnologies and engineering solutions to colorectal disease, nanoparticle applications for cancer (incl. quantum dots & liposomal particles), intelligent instruments, medical robotic technologies, haptic sensing systems, devices for incontinence, molecular biology, microbiome research and novel markers of response to neoadjuvant treatment.





Our <u>vascular theme</u> – led by Professor Julian Scott – an ageing population and rising levels of obesity and type II diabetes are increasing the prevalence of peripheral arterial disease (abdominal aortic aneurysm and lower limb ischaemia) can ensue.

**Areas of expertise:** Abdominal Aortic Aneurysms, Thoracic Aortic Aneurysm, Novel vascular stents, 3D printing and flexible tubular replicas of abdominal aortic aneurysms, automatic 3D segmentation of complex anatomical structures, spray technologies for endoluminal thrombolysis, novel small-molecules as therapeutic targets in vascular disease, virtual vascular suturing, wound management, diabetic foot ulcers and peripheral arterial disease.



Primary and secondary liver cancer forms a large part of our <u>HPB theme</u>, led by Professor Giles Toogood. Other HPB cancers, such as hepatocellular and pancreatic cancer, are less common, but there has been little change in their dismal prognosis over several decades. This theme also covers benign conditions, including gall stone disease and its complications, and the increasing prevalence of pancreatitis due to alcohol abuse. **Areas of expertise:** nanoparticles for thermal ablation of metastatic disease, dual functional particles for intraoperative cancer localisation, haptic feedback systems for liver surgery, augmented reality liver resection, predictive value of resections in liver and pancreatic cancer, psychomotor skills and operative safety in laparoscopic surgery.

#### Leadership of Surgical MedTech Co-operative

#### **Professor David Jayne – Clinical Director**

David Jayne is Clinical Director for the Surgical MedTech Co-operative. He is Professor of Surgery at the University of Leeds and Honorary Consultant Surgeon at the Leeds Teaching Hospitals NHS Trust. He is a NIHR Research Professor and brings expertise in the identification of unmet needs related to colorectal disease, the development of surgical technologies through interdisciplinary working, and clinical translation through early and late phase clinical trials.

His clinical interests include minimally invasive and robotic colorectal surgery. His research interests include the development, application, and evaluation of new technologies for surgical application. In 2012 he was awarded an NIHR Research Professorship to promote the translation of novel technologies into clinical practice for patient benefit. He is CI on several NIHR portfolio clinical trials:

- NIHR HTA FIAT (anal fistula plug v surgeon's preference)
- NIHR EME ROLARR (robotic v laparoscopic surgery for rectal cancer)
- NIHR EME GliSten (next generation fluorescent lymph node mapping in colon cancer)
- NIHR HTA Fenix (magnetic anal sphincter for faecal incontinence)

#### Professor Giles Toogood – HPB Lead

Giles Toogood is Professor of Hepatobiliary Surgery at Leeds University and has been a Consultant at St James's University Hospital, Leeds since 1998. He trained at Oxford University and completed his hepatobiliary and transplant training in Oxford, Cambridge and Australia. He also completed his Doctor of Medicine at Oxford University. He performs liver cancer and liver transplantation surgery and works in one of the largest Units in Europe.

He has published over 160 peer reviewed publications and has supervised several post graduate fellows towards PhDs and MDs.

Giles is currently Principal external examiner for Oxford University Medical School and examines for the Intercollegiate Specialty Board in General Surgery and also for the Union Européenne des Médecins Spécialistes in HPB Surgery.



He was on the NICE guidelines group for gallbladder disease. He is President Elect of the Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland and was the Founder President of the Great Britain and Ireland Hepatopancreatobiliary Association, (2009). He is also a member of the European and African HPB Association Training Committee.

Giles played cricket for Worcestershire CCC between 1978 and 1982. He played first class cricket and rugby for Oxford University in the 1980s and played Minor Counties Cricket for both Shropshire and Cambridgeshire. He is currently a member of the MCC main Committee and captained MCC on two major tours.

#### Professor Julian Scott – Vascular Lead

Professor Scott trained in Leicester, Peterborough, Bristol, Exeter, Gloucester and Melbourne and was appointed as a consultant vascular surgeon in November 1993.

He has a large NHS practice based at the LGI and takes part in the major trauma centre. He was appointed as an honorary professor of vascular surgery at the University of Leeds in 2004 and manages a large academic research group, focused on abdominal aortic aneurysms, based within the Leeds Institute of Cardiovascular and Metabolic Medicine.

He has extensive experience of the management of arterial and venous disease.

He works closely with colleagues in interventional radiology, and offers minimally invasive approaches to arterial and venous disease.

He is an advisory member of the BHF, Past Chairman of the European Board of Vascular Surgery and the current FRCS Vascular Examination Board and the lead for Academic Foundation and INSPIRE at the University of Leeds.

He is also President Elect of the Union Européenne des Medécins Spécialistes (UEMS) Section and Board of Vascular Surgery and a Past-President of the Vascular Society of GB and Ireland (2012-13).