

UKCRF NETWORK

In partnership with



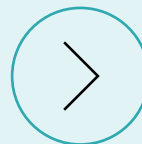
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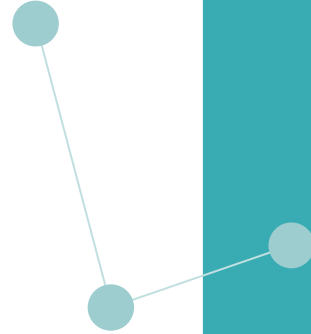


UKCRF
NETWORK

**Leading
collaborative
experimental
medicine
research delivery**

across the UK and Ireland

2023-2029



UKCRFNETWORK

Clinical Research Facilities provide...

[Skip to Menu >](#)

Purpose-built, flexible
clinical research spaces



UKCRFNETWORK

Clinical Research Facilities provide...

[Skip to Menu >](#)

**Purpose-built, flexible
clinical research spaces**

**World-class equipment
and technology**



UKCRFNETWORK

Clinical Research Facilities provide...

We have over 50 Clinical Research Facilities (CRFs) with over 110 individual units across the UK and Ireland

**Purpose-built, flexible
clinical research spaces**

**World-class equipment
and technology**

**Highly skilled, agile and
experienced workforce**



UKCRFNETWORK

We share



Expertise

Highly experienced
in early phase and
high intensity studies

Developing, sharing
and implementing
best practice



UKCRFNETWORK

We facilitate



Coordination

Streamlined
access to CRFs

Rapid turn-around
of expression of
interest requests



We succeed through



Collaboration

Tackling barriers
to experimental
clinical research

Working across
the research
infrastructure



We ensure



Patient focus

Patients and
volunteers at the
heart of research

Understanding their
experience to improve
study design and delivery



UKCRFNETWORK

Together we deliver

Networked experimental medicine

Investigating new treatments and interventions in humans, to better understand safety, effectiveness, and potential impact on specific diseases and conditions.



UKCRFNETWORK

Together we deliver

Early translational research

Turning scientific discoveries into practical solutions that benefit people's health and well-being.



UKCRFNETWORK

Together we deliver

Clinical trials to rigorous safety standards

We are the gateway to delivering cutting edge experimental medicine clinical research across the UK and Ireland.



UKCRFNETWORK

Welcome to the UK Clinical Research Facility Network

WE HAVE

over 20 years'

experience facilitating collaboration
between Clinical Research Facilities (CRFs)
and stakeholders.



Implementing
operational excellence and
developing best practice



Building
quality strategic partnerships
with research funders



Nurturing
a growing and dynamic
workforce



Promoting
Involvement, inclusion and
participation in clinical research

UKCRFNETWORK



“ **Staff across over 50 CRFs collaborate with passion and dedication**, to benefit patients and the public and allow them greater opportunities to take part in experimental medicine clinical research.

We look forward to expanding our teams and continuing our growth and success over the next five years”

Paul Brown, UKCRF Network Operational Director



“ **The UKCRF Network builds genuine collaborations and relationships** between CRF staff, partner organisations and patients, allowing us to share best practice and improve standards without barriers getting in the way.

Our ambition is to build on the breadth and scope of the work we’ve already undertaken, to influence the delivery of experimental medicine at scale across the UK and Ireland”

Caroline Saunders, UKCRF Network Deputy Operational Director

UKCRFNETWORK



“ Our Clinical Research Facilities provide **the safest possible environment for children and adults** to take part in early development trials for new medicines, vaccines and diagnostic technologies.

The UKCRF Network supports industry and public trials in all specialities to be set up and delivered as quickly as possible”

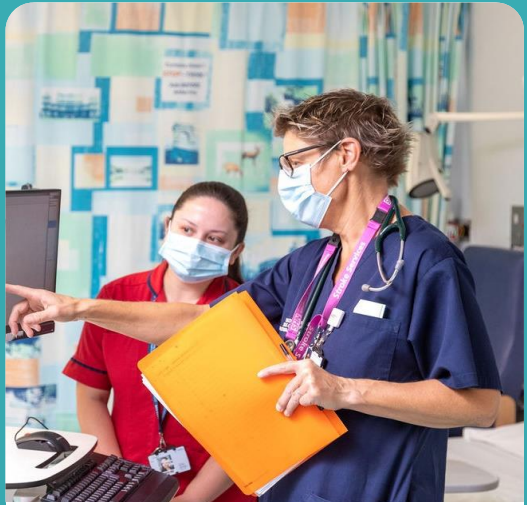
Professor Saul Faust, [UKCRF Network Clinical Lead](#)



“ Manchester is very proud to continue hosting the UKCRF Network at Manchester University NHS Foundation Trust.

The increased funding will benefit clinical research delivery and support staff across the Network. We will provide more opportunities for collaboration and professional development, and contribute to the growth of health and care research”

Professor Jacky Smith, [UKCRF Network Deputy Clinical Lead](#)



About CRFs
& the UKCRF
Network

Learn more →



Supporting
CRF Operations
& Workforce

Learn more →



Working
with Industry
& Funders

Learn more →



Public
Involvement
& Inclusion

Learn more →

About us

A Typical CRF

Mapping CRFs across
the UK & Ireland

Our Work Programme



A Collaborative Network



The UKCRF Network is led by a Senior Leadership and Management Team, with Work Package Leads and Deputies delivering our work programme, supported by work groups and a central operations team.

Our leaders are appointed from CRFs across the UK and Ireland utilising our expertise to drive forward actions and coordinate a national early phase research delivery platform as 'one CRF'.

In 2023, the National Institute for Health and Care Research (NIHR) awarded five years of increased funding to expand and enhance the Network programme of work.

We are funded by



National Institute for Health and Care Research

Hosted by



Manchester University
NHS Foundation Trust

In partnership with




Ymchwil Iechyd a Gofal **Cymru**
Health and Care Research **Wales**



UKCRF Network Organogram →

A Typical CRF

Whilst each CRF has their own mix of specialities and staff; as a minimum, each CRF comprises everything needed to deliver high-intensity studies.

CRFs are embedded within host organisations, which are typically NHS Hospitals. They function within their host's established clinical governance and operational frameworks, and work with the host's research and development (R&D) office to complete costing, contracting and local approvals for all studies.

CRFs maintain stringent adherence to national research regulatory standards, ensuring exceptional participant safety and research quality.

[Take a Tour of our CRFs →](#)

Clinical Research Facilities typically include:

- Participant ward areas, clinics and consultation rooms
- Laboratory, for sample processing, storage and management
- Space for hosting monitors
- Drug preparation facility or access to pharmacy
- Access to imaging capabilities (e.g. MR, CT, PET and others)
- Reception area and participant lounge
- Document storage
- Integrated hospital systems
- Access to patient and public groups



UKCRFNETWORK

World Class Specialist Facilities

Across our CRFs, we have specialised facilities and equipment to trial unique and innovative treatments in a safe environment, accessible both within CRFs themselves, and across the wider hospital and local infrastructure.



Here is a sample of what we have to offer across the Network:

**Dental
Research
CRFs**

**Neurology
centres**

**Metabolic
research
facilities**

**Sleep
Research
centres**

**Gene
therapy
facilities**

**Endoscopy &
Bronchoscopy
suites**

**Exercise
physiology
suites**

**Mental Health
& Dementia
facilities**

**Mobile
Research
units**

Our Workforce



CRFs have dedicated staff who are highly trained and experienced at delivering complex and high intensity, experimental medicine clinical research.



As well as the list on the right, some CRFs have Advanced Nurse Practitioners, Physician Associates, Recruitment Managers, Play Specialists and other Allied Health Professionals. CRFs may also expand their workforce to meet the needs of a study.

A CRF typically includes:

- Operational Manager
- Clinical Director
- Matron / Nurse Manager / Lead Nurse
- Clinical Research Nurse / Midwife
- Clinical Research Practitioner
- Clinical Fellow / Junior Doctor
- Administrator
- Research Assistant / Coordinator
- Data Manager / Officer
- Quality Assurance Lead
- Clinical Educator / Practice Development Nurse
- Laboratory Technician / Manager
- Public Involvement & Engagement Lead
- Specialised staff, such as Clinical Trials Pharmacist, Nutritionist and Physiotherapist

Mapping CRFs Site across UK & Ireland

KEY

- NIHR Funded
- HRB Funded
- CSO Funded
- Other

Dublin

- St James CRF
- Royal College of Surgeons
- University College Dublin CRC
- Children's Health Ireland CRC

Liverpool

- Alder Hey CRF
- Liverpool CRF

Clinical Translational Research and Innovation Centre

Northern Ireland CRF

Galway CRF

Limerick Clinical Research Support Unit

Cork CRF

Cardiff

- Cardiff Adult CRF
- Children & Young People Research Unit

Highland CRF

Glasgow CRF

Lancashire CRF

Manchester CRF

North Wales CRF

Sandwell & West Birmingham CRF

Birmingham CRF

Plymouth CRF

Exeter CRF

Bristol CRF

Southampton CRF

Aberdeen CRF

Dundee CRF

Fife CRF

Edinburgh CRF

Newcastle CRF

Leeds CRF

Sheffield CRF

Sheffield Children's CRF

RDaSH Community CRF

Nottingham CRF

Leicester CRF

Coventry & Warwickshire CRF

Norfolk CRF

Cambridge CRF

East Kent CTU Facility

Royal Surrey CRF

Brighton & Sussex CRF

London

- Barts CRF
- Great Ormond Street Hospital CRF
- Guy's & St Thomas' CRF
- Imperial CRF
- Moorfields CRF
- Royal Free CRF
- The Royal Marsden CRF
- King's CRF
- St George's CRF
- UCLH CRF

- Chelsea and Westminster CRF
- Northwest London CRF
- Pears Maudsley for Children and Young People CRF

Oxford

- Oxford CRF
- Oxford Health CRF

- Oxford Cardiovascular CRF

Our Work Programme

The UKCRF Network has four **work packages** to achieve our key objectives. These are delivered by a work package Lead, Deputy, Work Group Chairs and group members.



Operational Delivery

- Tackling barriers to experimental medicine clinical research
- Developing, sharing and implementing best practice



Strategic Leadership

- Streamlined access to CRFs
- Building strategic partnerships with research funders & sponsors



Workforce Development

- Meeting the needs of an evolving workforce
- Working across the research infrastructure



Involvement & Inclusion

- Promoting public involvement and research inclusion
- Improving patient experience, study design and delivery

Work Package Leads

Operational Delivery

LEAD:

Joanna Gray

Clinical Manager,
NIHR Birmingham CRF



DEPUTY:

Elka Giemza

CRF Manager,
NIHR Kings CRF

Strategic Leadership

LEAD:

Dr Helen Radford

Associate Director of
Operations, R&I, Leeds



DEPUTY:

Frances Doyle

CRF Manager,
NIHR The Royal
Marsden CRF

Workforce Development

LEAD:

Jennifer Allison

Lead Matron,
NIHR Southampton CRF



DEPUTY:

Naomi Hickey

Education and
Quality Lead,
Glasgow CRF

Involvement & Inclusion

LEAD:

Caroline McMahon

PPI Lead,
NIHR Cambridge CRF



CO-DEPUTIES:

Kate Dodd (PPIE)

Recruitment & Engagement
Manager, NIHR Liverpool CRF

Tracy Gazeley (EDI)

CRF Manager, Coventry CRF

Work Groups

We have work groups to support our work programme and provide opportunities for peer support, sharing best practice and overcoming challenges.



Operational Delivery

- CRF Managers
- Laboratory Managers
- Study Intensity



Strategic Leadership

- Industry Liaison
- Information Management & Technology (IM&T)
- Expressions of Interest Request Review Group



Workforce Development

- Clinical Research Delivery
- Quality Assurance (QA)
- Training & Education
- Leadership Programme Trainers



Involvement & Inclusion

- Public Involvement
- Research Inclusion

UKCRFNETWORK

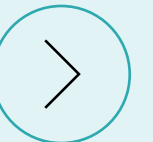
Supporting CRF Operations & Workforce



How we achieve
operational excellence (WP1)

How we nurture our
workforce (WP3)

Development opportunities
for staff



Operational Delivery



We focus on sharing best operational practice, overcoming operational challenges and maintaining effective communications within the Network.

We are building on the exemplary collaboration we saw during COVID-19, to facilitate networked experimental medicine and early phase trials, accelerating trial delivery and supporting single-site, multi-site and international research.

In partnership with colleagues, we are committed to nurturing and developing new and emerging Managers, to ensure sustainable, successful leadership for CRFs.

Achievements (2017-2022)

- ✓ Facilitated cohesive and engaged CRF Manager and Lab Manager groups that meet regularly to work through operational challenges and share practice
- ✓ Designed a leadership development programme and appointed CRF expert facilitators
- ✓ Further developed the Study Intensity Tool, which remains the only nationally validated workforce planning tool for clinical research. This tool is widely used across clinical research delivery teams throughout the UK and Ireland
- ✓ Delivered a collaborative, coordinated response across all CRFs to the pandemic, supporting national vaccines, therapy and diagnostic trials

Operational Delivery



Work Package Leads

LEAD:

Jo Gray



Head of R&D

Operations, University

Hospitals Birmingham NHS FT;

Clinical Manager,

NIHR Birmingham CRF

DEPUTY:

Elka Giemza

CRF Manager,

NIHR King's CRF

Vision for the future (2023 – 2029):

- Promote inclusive and engaged Network membership, encouraging all CRFs to integrate into the Network to support consistent operational excellence
- Continue to support ongoing development needs of CRF Managers by providing peer support, mentorship, and supervision
- Continue to develop, share, and implement best practice guidelines and tools to aid study delivery, ensuring staff have the required expertise and training for the effective use of these tools

Networking Opportunities

We bring together staff groups for peer support, the sharing of best practice and education.

By networking with other CRFs we avoid duplication of effort, improve skills, and introduce more efficient ways of working.



Opportunity for CRF Networking:

- Represent your CRF on one of our work groups to develop and share best practice. Each group has its own distribution list for group members to keep in contact with each other. There are limited spaces per CRF, so please speak with your CRF Manager.
- Attend our Annual Conference for group discussions and workshops.
- Attend CRF training webinars and programmes ([visit our website](#)).
- Contact the UKCRF Network Operations Team to get in contact with CRFs conducting similar clinical trials or to circulate requests for information: ukcrf.network@nihr.ac.uk

Access Best Practice

We develop guidelines, training materials, tools and checklists to support CRF operational excellence and workforce development.

All documents can be downloaded from the [UKCRF Network Portal](#), a simple and secure online platform.



Example of the operational tools we have to offer:

➤ Study Intensity Tool

A standardised and validated tool for accurately assessing study workload. The tool efficiently calculates the necessary staff resources for individual and multiple studies.

➤ Early Phase Governance Framework

A framework to guide the enhanced governance processes that allow CRFs to work to a minimum agreed standard for the highest risk studies.

➤ Internal Audit Toolkit

For the development of an internal audit function, complete with audit templates, spreadsheets and guidelines.

➤ Dosing Day Final Safety Checklist

A checklist to ensure all safety governance procedures are in place prior to exposing participants to investigational medicinal products.

CRF Excellence in Practice

Operational Excellence



Development for multiple myeloma treatment

The NIHR University College London Hospitals CRF played a vital role in the successful development and approval of belantamab mafodotin (belamaf) for multiple myeloma (MM) treatment.

The Outcome

Their operational excellence ensured efficient delivery of the early phase DREAMM trials, with the CRF serving as the highest global recruiter for one of the cohorts. These achievements contributed to a multi-site trial, increased investment, and subsequent approval of belamaf in 2020.

The CRF's expertise and collaboration with other CRFs enabled the implementation of the ProMMise trial, testing belamaf in novel treatment combinations. With approximately 6,000 new MM patients annually, these milestones and ongoing research projects offer hope and improved outcomes. The CRF's comprehensive support in trial management, data collection, and coordination has been instrumental in advancing MM research.

Collaborating for Success

Uniting forces in urgent COVID-19 Trials

CRFs worked collaboratively to deliver COVID-19 research at pace and scale, across a range of early phase experimental medicine through to late phase trials, covering diagnostics, pathophysiology, treatment, follow-up and prophylaxis.

CRF Directors acted quickly to promote CRF expertise and collaborations to national leaders, ensuring the quick placement and set-up of early phase therapeutic and vaccine studies.

CRF Managers met monthly to share new ways of working and overcome challenges, removing barriers to the delivery of urgent public health research.



All CRFs showed great flexibility, adaptability and collaboration in response to the pandemic.

We contributed to:

- ★ Record recruitment numbers of research participants, with over half a million people taking part in pioneering COVID-19 research
- ★ The development of new treatments, including the discovery of the first life-saving drug
- ★ The development of vaccines and prevention, working quickly to set up large scale complex vaccination studies



Play videos

Workforce Development



We focus on assessing workforce skills and training requirements to develop and co-design learning skills packages to meet the needs and wellbeing of a multidisciplinary, professional and agile workforce.

We seek collaborations to improve the experience and environment for participants and staff in CRFs, linking with NIHR, NHS, Higher Education Institutions and others to deliver advanced workforce development opportunities for CRF Leaders and staff.

We are advocates for colleagues responsible for the high-quality, safe, and efficient delivery of experimental medicine, whilst considering public involvement and research inclusion.

Achievements (2017-2022)

- ✓ Developed best practice safety and workforce training guidelines for local and national use
- ✓ Supported workforce challenges, for example during COVID-19, staff benefitted from virtual peer support meetings, helping them adapt to new ways of working and deliver large scale vaccination studies
- ✓ Designed and launched a summer school format for the Network's Annual Conference, bringing together expertise from across the Network to deliver engaging, collaborative and interactive workshops

Workforce Development

Work Package Leads

LEAD:

Jennifer Allison

Lead Matron, NIHR
Southampton CRF;
NIHR Associate Director of
Nursing and Midwifery



DEPUTY:

Naomi Hickey

Training & Quality Lead,
Glasgow CRF

Vision for the future (2023 – 2029):

- Attract new staff, expand career pathways, and retain talent by leveraging existing collaborations across the full remit of research delivery, including stakeholders
- Implement CRF mentorship to support succession planning within CRFs and across UKCRF Network, creating a framework that is adaptable for all workgroups
- Develop a framework for health and wellbeing strategies to provide resilience within the research delivery workforce

Training and Development

We offer a range of training and development opportunities to foster an experienced, highly skilled and agile workforce.



[Training opportunities on our website >](#)

The UKCRF Network develops training documents for local implementation, many of which have been adopted by delivery teams across the wider clinical research infrastructure.

Training tools include:

- Clinical Research Induction Framework
- Competency Assessment Templates
- Emergency Scenario Training Guidelines
- Laboratory Skills Training Toolkit

We deliver bespoke training programmes:

- Leadership Programme for Managers
- Online Study Intensity Tool training

We deliver interactive workshops at our Annual Conference.

We promote training opportunities from across the Network and partner organisations on our website.

Annual Conference

We bring together CRF staff, stakeholders and public contributors to network, share best practice and develop new skills, at our in-person conference.



- Designed to meet the needs of staff delivering early phase clinical trials
- High profile national speakers to cover a wide variety of current and important topics
- Interactive 'Summer School' sessions to provide engaging and in-depth workshops
- Posters to showcase CRF excellence and innovation
- Opportunities to network and learn from experts in trial set-up and delivery
- Discussions with sponsors to prepare for the complex trials of the future
- A forum to meet patients and the public who are shaping the research we do

[Learn about our next conference >](#)



CRF Excellence in Practice

Workforce Development



To successfully meet high and urgent recruitment targets for COVID-19 vaccination studies in 2020, various healthcare professionals were required, including research nurses, healthcare support workers, and clinicians from different specialties.

Glasgow CRF therefore established a new role —the Project Site Manager

This Manager was responsible for overseeing and coordinating all study activities, from feasibility to final archiving. Serving as a central point of coordination, they communicated with all involved parties to ensure the smooth and accurate conduct of the studies. Working across different teams, the Project Site Manager provided valuable support for departmental issues, audits, and specialist advice. Their primary focus was to ensure the safe implementation of studies according to protocols, allowing research nurses to dedicate more time to patient-focused tasks and maintain the highest standards for each aspect of the study.

The introduction of this new role also resulted in direct benefits for study participants. They received timely updates and had a dedicated point of contact, which encouraged engagement and participation.

UKCRFNETWORK

Working with Industry and other Research Funders

Our offer to life science industry,
medical research charities & other
research funders (WP2)

Our capacity and capability

How we fit within the infrastructure



Strategic Leadership



Working with NIHR industry leads, we provide an early phase and complex trial offer to life science industry, medical research charities and other research funders.

We work with stakeholders to promote CRFs as an integrated national platform.

We support and collect data on CRF capability and capacity, and work with research funders and sponsors to identify CRFs and principal investigators that meet their study requirements.

Achievements (2017-2022)

- ✓ Promoted the collective strength of CRFs and the Network to pharmaceutical companies
- ✓ Developed an efficient and effective system for the coordination of rapid responses to expression of interest requests, streamlining the process and reducing duplication
- ✓ Developed new relationships with industry, providing accelerated access to CRFs and the set up of clinical trials.

Strategic Leadership

Work Package Leads

LEAD:

Dr Helen Radford



Associate Director of Operations for
Research, Leeds Teaching Hospital
NHS Trust

DEPUTY:

Frances Doyle

CRF Manager,
NIHR The Royal Marsden CRF

Vision for the future (2023 – 2029):

- Build a system to encourage and maintain collaborative working and strategic partnerships with the life science industry, medical research charities and universities, enhancing our 'one-CRF' approach
- To continue to strengthen our capacity and capability database, and working with national bodies to ensure more real-time data is available on CRF and NHS delivery of early phase clinical trials
- To continue to overcome key barriers to early phase research and ensure that CRFs play a key role in realising the ambitions set out within the government's vision for the future of clinical research delivery
- To work across NIHR and all stakeholders to develop and implement the National Contract Value Review for early phase and ATIMP (advanced therapy investigational medicinal product) trials

Working with Industry & Research Funders

The UKCRF Network supports the life science industry, medical research charities and other organisations by providing streamlined access to our CRF.

Providing access to pioneering science and facilities, through matching clinical trial requirements with CRF expertise, experience and facilities.

As well as the services on the right, we also build strategic partnerships to enhance our 'one-CRF' approach and provide access and support across the clinical research pipeline.

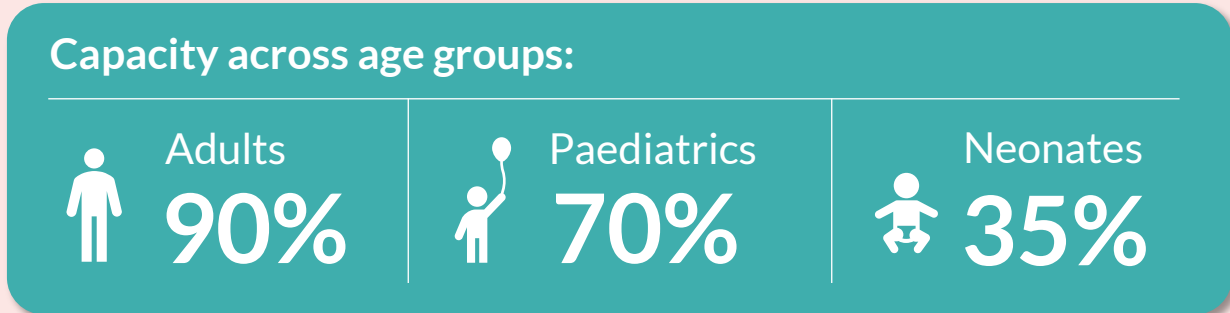


Our Services

- We work in partnership with the NIHR as part of a 'single point of contact' process for all expressions of interest (EOI) requests: industry@nihr.ac.uk
- We identify CRFs that are equipped to deliver a trial
- We review and circulate EOI requests to appropriate CRFs and collate responses
- We work with CRFs to ensure rapid turn-around of requests and study set-up
- We identify key opinion leaders and delivery staff for specific advice or delivery on trials
- We can provide guidance on protocol design and study delivery, using professional and patient advisory groups

Our Capacity & Capability

The UKCRF Network has over...



219,981 participant visits from 22 NIHR CRFs (2018/19)

50% commercially funded studies

CRF experience:

Phase I
95%

First in human
80%

Dose escalation
75%

Capacity across Health Care Categories:

Cancer & neoplasms	90%
Neurological	92%
Inflammatory & immunity	95%
Metabolic & endocrine	87%
Infection	89%
Oral & gastrointestinal	86%
Cardiovascular	90%
Respiratory	87%
Eye	68%
Mental health	64%
Musculoskeletal	85%
Generic health relevance	77%
Renal & urogenital	86%
Blood	85%
Congenital disorders	74%
Reproductive health & childbirth	69%
Skin	82%
Ear	66%
Injuries & accidents	53%
Stroke	81%
Sleep	69%

CRF Excellence in Practice

Strategic Leadership



Enabling simultaneous testing of multiple drugs

The NIHR Liverpool CRF created the AGILE platform trial in collaboration with University of Liverpool and Southampton Clinical Trials Unit, a first-in-human phase I/IIa study, that enables simultaneous testing of multiple drugs and swift adjustments based on safety and efficacy outcomes.

This ground-breaking initiative involved collaboration among several CRFs within the UKCRF Network: Liverpool, Southampton, Manchester, Lancashire and King's London. The CRFs worked together to overcome challenges, share standard operating procedures and utilise a unified recruitment system.

Leveraging the specialist infrastructure and expertise of CRFs resulted in the efficient recruitment of participants, and safe delivery of the trial within a short timeframe. The study successfully supported the regulatory approval of the first antiviral drug used to treat COVID19, Molnupiravir.

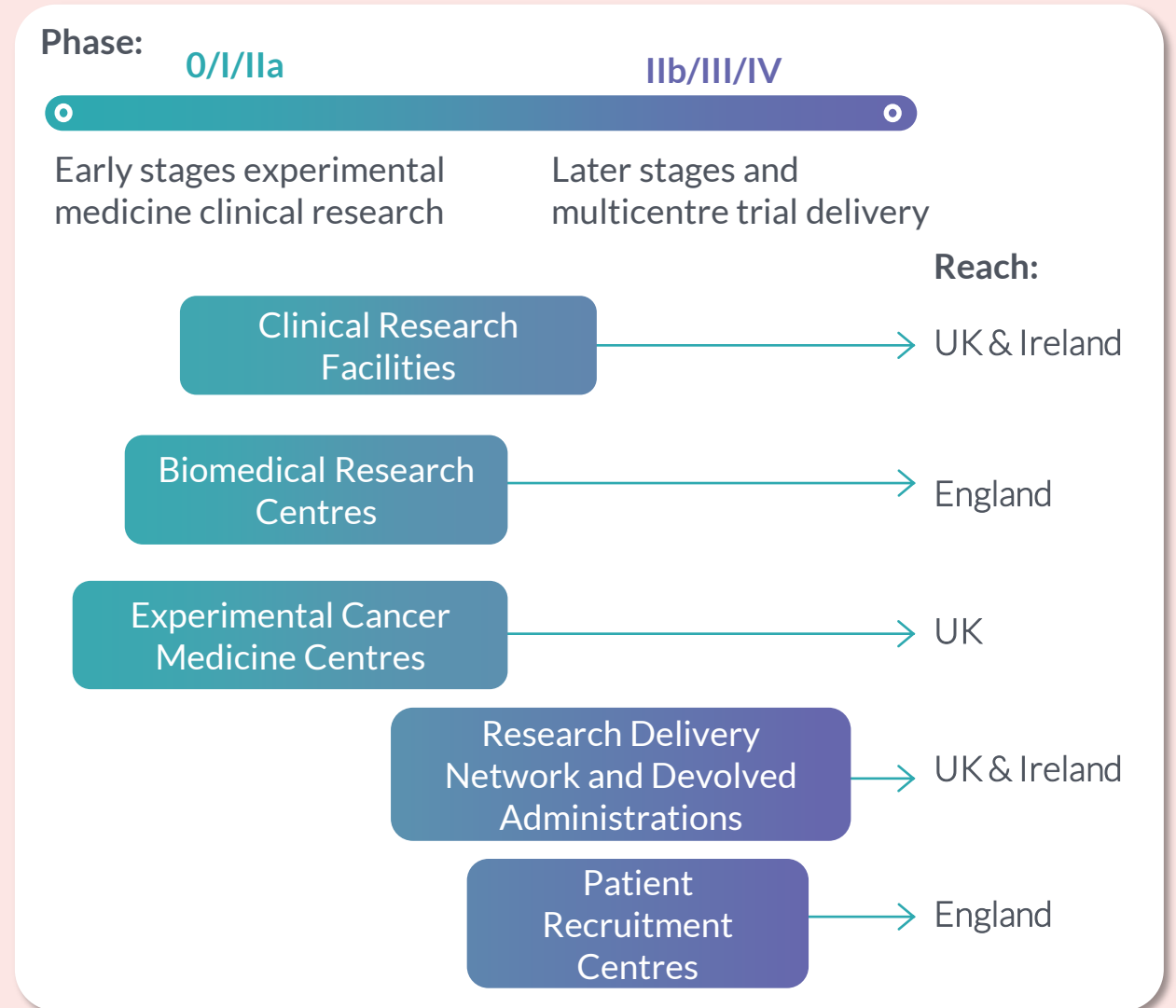
The AGILE platform design and enhanced collaboration offers a clear model that can be utilised by CRFs for other studies and disease areas.

The Experimental Medicine Infrastructure

The UK and Ireland infrastructure enables researchers to develop clinical applications from scientific breakthroughs, to translate these discoveries into new treatments for patients.

CRFs are designed to deliver early phase experimental medicine clinical research and later phase, complex, high intensity studies.

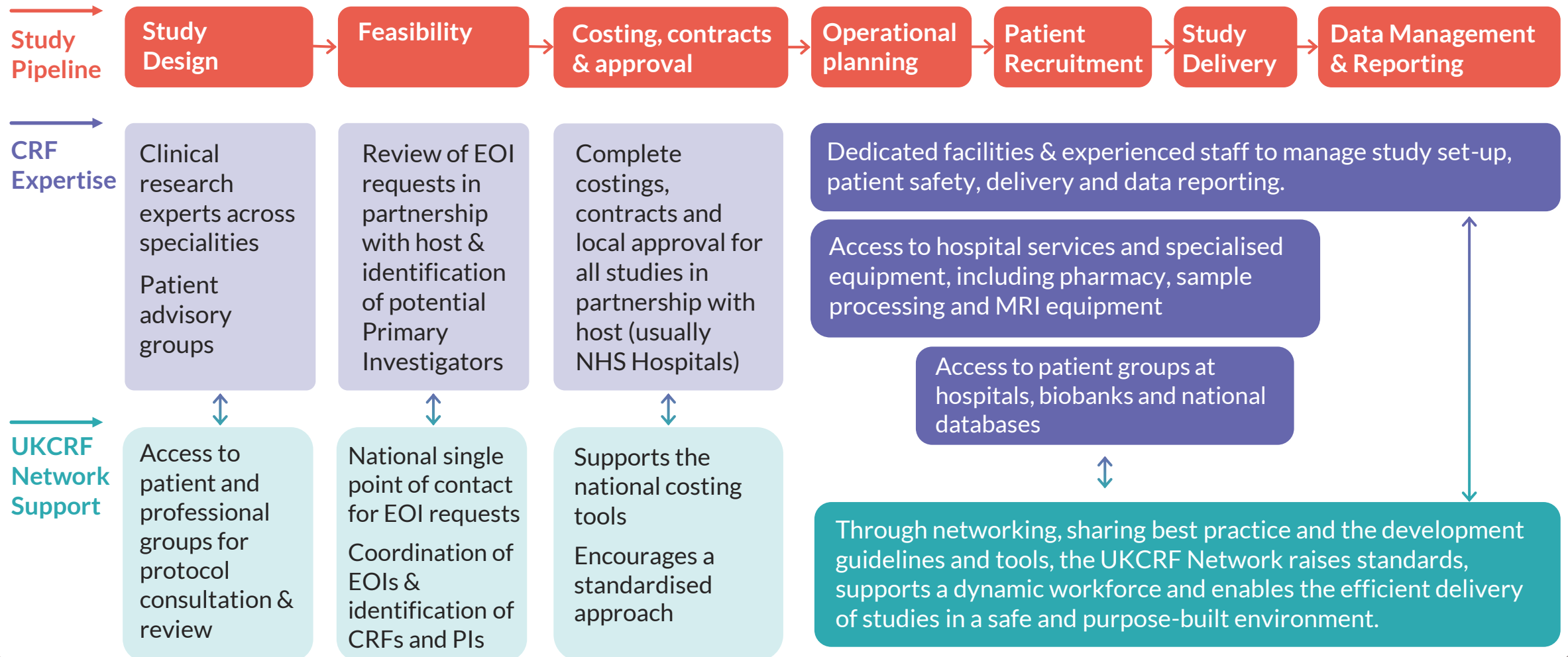
We work closely with NIHR Biomedical Research Centres which translate lab-based scientific breakthroughs into potential new treatments, diagnostics and medical technologies, and we collaborate with the NIHR/CRUK Experimental Cancer Medicine Centres who increase the capacity, safety and speed of early-phase cancer research.



[Learn about about the wider infrastructure](#) >

The Clinical Research Pipeline

This diagram shows an example of how Clinical Research Facilities and the UKCRF Network support the set-up and delivery of experimental medicine studies.



Public Involvement and Inclusion

GLOSSARY OF TERMS



Involvement and Inclusion



CRFs work in partnership with the public and patients to improve the way we set up and deliver research, enhance the participant experience, and promote inclusive trial participation.

By sharing best practice, collaborating and providing peer support, we enable CRFs to raise awareness of clinical research through engagement, involvement and participation strategies to overcome inclusion challenges.

We actively encourage public involvement in the governance and operational structures of the Network, ensuring we have public representation across everything we do.

Achievements (2017-2022)

- ✓ Developed an active and dedicated group of Patient and Public Involvement and Engagement (PPIE) Leads who work together to develop best practice, implement effective strategies (putting plans into action for success) and provide peer support for overcoming challenges
- ✓ Built strong relationships with national leaders, aligning our work with UK standards and contributed to national guidelines and training
- ✓ Embedded public and patient contributors within our Network Annual Conference, showcasing heart-warming and impactful patient stories, co-produced workshops and provided opportunities for joint discussions across a range of topics
- ✓ Conducted patient experience and research awareness surveys which impacted on CRF and local host Trust research delivery and staff training

Involvement and Inclusion

Work Package Leads

LEAD:

Caroline McMahon

Public and Patient Involvement
Lead, NIHR Cambridge CRF



CO-DEPUTIES:

Kate Dodd (PPIE)

Engagement
& Recruitment Manager,
NIHR Liverpool CRF

Tracy Gazeley (EDI)

CRF Manager
Coventry CRF

Vision for the future (2023 – 2029):

- Embed public involvement and inclusive research within the culture and governance structures of the Network, including representation on project delivery groups
- Provide enhanced opportunities for leadership development and peer mentoring for Patient and Public Involvement and Engagement (PPIE) Leads, and Equality Diversity and Inclusion (EDI) Leads
- Develop a comprehensive library of CRF involvement examples to share best practice, with a focus on engaging people from under-represented communities

CRF Excellence in practice

Involvement & Inclusion



Young Patient and Family Involvement in Industry Sponsored Trials

Including patient groups in protocol review ensures a greater understanding of patient needs and requirements, encouraging greater retention and protocol adherence.

The Outcome

The NIHR Clinical Research Network (now the Research Delivery Network) launched a national 'Patient Engagement in Clinical Development' service to enable patient and public groups in the improvement of study design and delivery.

NIHR Alder Hey CRF successfully piloted this service using both a paediatric and a parent/carer group, resulting in improvements to the study protocol.

Following the pilot, the pharmaceutical company involved has committed to engaging with patients for all studies and has continued to work with focus groups at Alder Hey.

Be Part of Research

Clinical research would not be successful without the involvement of patients and the public.



Contact your local CRF >

Sign-up via the NHS app >



How YOU can get involved

There are many kinds of health and social care research, and many crucial roles throughout the process that you can get involved with:

- Take part in clinical trials (participation)
- Join patient advisory boards for input on research (involvement)
- Share experiences in focus groups or surveys (involvement)
- Review information and give advice (involvement)
- Become a Research Champion (engage others)

By being involved in Clinical Research, you help us improve the reach, quality and impact of our research, whilst also actively contributing to advancements in healthcare.

CRFs have dedicated expert staff to support and facilitate public and patient involvement, engagement and participation.

Empowering the Public and Patients: Real-life experiences

Participating in clinical research can provide invaluable access to new treatments and an opportunity to contribute to important medical improvements.



I had a great time, and learnt loads about my body, as well as helping the team with their research”

**Immy, paediatric research participant,
NIHR Cambridge CRF**



It was so exciting meeting some of the huge team of people working on the vaccine, especially so during the height of the first lockdown. I learnt a lot about how vaccines work and how pharmaceuticals are developed, and it was great asking questions to all the friendly doctors and nurses I met during my appointments.

I would definitely volunteer again. I hadn't really expected how exciting and rewarding it would feel to be involved- it's really been such a positive experience all round"

Georgina (with Mother, Chloe),
Research Participants, NIHR Imperial CRF



The place itself and the people, from the cleaners to top consultants, instilled an air of confidence in me that I was going to get better. On the (clinical) trial, that never diminished really, because of the impressive results.

It (the cancer) returned very quickly, and I came in very ill, but in a month and a half I was feeling pretty good. I didn't think I would see my 70th birthday, or my 50th wedding anniversary and I've seen both!"

John, Research Participant,
The Christie, NIHR Manchester CRF

Improving Patient Outcomes



The Study

NIHR Moorfields CRF delivered a study to investigate whether initial treatment with laser would improve quality of life in patients with glaucoma & ocular hypertension

The Outcome

The study successfully found that later treatment reduced the number of cataract surgeries, and removed the need for glaucoma surgery in the first three years.

NICE have since updated their guidelines to recommend much greater use of Selective Laser Therapy. Uptake by all affected patients has the potential for savings of up to £250 million for the health and care system.

Turning Discovery into Practice

New drug for children with deep vein thrombosis



The Study

NIHR Birmingham CRF delivered the Einstein Study to test the use of oral Rivaroxaban in children, a treatment option for deep vein thrombosis (DVT) that does not rely on injection or blood sampling.

The Outcome

Robust and efficient screening ensured recruitment targets were met to time and target, including recruitment to the lowest age group and a patient with comorbidities.

Rivaroxaban has been successfully licensed for use in the EU including the UK in children from birth to 18 years old, providing patients a safe non-invasive procedure for DVT that provides significant cost savings for the UK health system.

Be Part of Research

Useful Links for Patients and the Public

- [How to take part in research](#)
- [Opportunities within the NHS](#)
- [Contact your local CRF](#)
- [Public Information Pack](#)



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