NIHR | BioResource

Toolkit for Building Trust and Representation

ALL IN FOCUS

IBHO
IMPROVING BLACK HEALTH OUTCOMES

NIHR | BioResource

TABLE OF CONTENTS

1

PURPOSE OF THIS TOOLKIT

The Improving Black Health Outcomes (IBHO) initiative is a national effort to improve representation, trust, and meaningful engagement with Black African and Caribbean communities in health research.

Since its launch in 2024, more than 5,400 Black African and Caribbean individuals have joined NIHR IBHO BioResource — a powerful start, but still far from where we need to be. Many people still don't know what the BioResource is, others are unsure if it's for them, and some are worried about what happens to their data or whether they can trust the system at all.

The All in Focus campaign, delivered through the NIHR BioResource, exists to change that.

This toolkit is for anyone who wants to help increase participation in health research among Black African and Caribbean communities — whether you are a nurse, site team member, researcher, community organiser, or partner organisation, and whether or not you are connected to NIHR IBHO BioResource. Anyone committed to widening participation in health research is encouraged to use it.

This toolkit supports those involved in health research to:

1.

Understand why representation in research is so important.

2.

Recognise the history and present-day experiences that shape trust.

3.

Provide support to research nurses and delivery teams on how to engage in medical settings.

4.

Plan and deliver engagement that feels respectful, relevant, and grounded in community priorities.

5.

Build and *sustain* relationships with Black African and Caribbean communities, not just for a single project, but over time.

This toolkit is also intended to evolve.

Feedback:

Feedback from those using it is actively welcomed and will help to shape future improvements and updates.

Direction of reading:

It can be read from start to finish, or sections can be read as needed. Each chapter first explains the “why” and “what”, then offers clear, practical “how-to” steps. At the back, there are checklists that can be used when planning events, creating campaigns, working with the media, and maintaining long-term relationships.

Ready-to-use assets:

We’ve also developed a set of ready-to-use assets for sites and centres that are delivering the IBHO programme to make it easier to promote the programme and engage with Black African and Caribbean communities. Every asset has been shaped through co-creation, reflecting the language, imagery and messages that community members told us feel relatable, respectful and trustworthy. This includes social media graphics, short videos, posters and postcards. Each resource is designed to help teams start meaningful conversations and explain the purpose of the programme.

2

WHY REPRESENTATION MATTERS

Every medical breakthrough starts with data, and that data comes from people. When some communities are missing from that picture, medicine doesn't work as well for everyone.

Black African and Caribbean communities have been under-represented in health research for a long time.

That gap shows up in several ways:

Diagnosis:	Illness can look different on darker skin or present with different symptoms. Without enough data, those differences are too easily missed.
Treatment:	Genetic variations can affect how people respond to medications. If Black African and Caribbean DNA is not included in research, treatment plans may be less effective or less safe.
Prevention:	Public health guidance is often based on lifestyle, environment, and health patterns. If Black African and Caribbean lives are not represented, those recommendations do not fully speak to these communities.

Representation is not about ticking a diversity box. It is about fairness and effectiveness. When Black African and Caribbean communities are included in the data, the findings become more accurate, the treatments more effective, and trust in the system more realistic. People can see that medicine is being built *with* them in mind, not just applied *to* them.

Representation in language and imagery matters too. When people can see themselves in photos, films, and stories, it sends a simple message: **"This includes you. This is for you."** When they can't, the message is just as clear: **"This probably isn't for us."**

■3

THE CONTEXT: WHY TRUST HAS TO BE REBUILT, NOT ASSUMED

Distrust in medical research among Black African and Caribbean communities did not appear overnight, and it is not irrational. It is rooted in real histories of exploitation, exclusion, and unequal treatment.

From experiments on enslaved women without consent or anaesthesia in the 19th century, to the Tuskegee Syphilis Study where Black men were denied treatment so researchers could watch the disease progress, to the story of Henrietta Lacks, whose cancer cells were taken and used worldwide without her consent or benefit — these stories are part of the collective memory of Black African and Caribbean communities. They shape how people see medical institutions and research today.

Surveys have found that:

Many Black people report being treated differently in primary care because of their ethnicity. **“Patients report alarming lack of trust in NHS primary care providers”** **by NHS Race and Health Observatory (2025)**

A majority of Black Britons believe that white patients receive better care from the NHS than Black patients. **“The Black Community and Human Rights”** **by Joint Committee on Human Rights (JCHR) (September 2020)**

So, when someone hesitates to take part in research, they are not just reacting to a single leaflet or conversation. They are responding to a long pattern of unequal treatment, often reinforced by experiences in the present day.

3.1

What this means for anyone in health research

This history cannot be fixed by one person alone. It also cannot be ignored.

What can be done is:

- Acknowledge that mistrust is understandable, not a barrier to work around.
- Be honest about what you know, what you don't, and what you can change.
- Show, through your actions, that this time is different — more transparent, more accountable, and more collaborative.

Trust is fragile. It is built slowly, through consistent behaviour, and can be damaged quickly by one careless interaction or broken promise. This toolkit is designed to help put trust at the centre of any campaign work, not treat it as an optional extra.

3.2

Why NHS research staff matter and the difference one research nurse can make

Research nurses, midwives, healthcare assistants, trial coordinators and wider delivery teams are often the first — and sometimes the only — members of staff a potential participant speaks to. People in these roles may be the first trusted point of contact for someone deciding whether to take part.

The ability to slow down for a moment, to explain things in a way that feels human rather than clinical, or simply to acknowledge someone's feelings, can leave people from the Black African and Caribbean community thinking: ***"This is for me. I am seen. My wellbeing matters."***

Sometimes, a single conversation is the first time a person feels that research might include and value them. Those moments stay with people and shape not only whether someone says yes or no to a single study, but how they talk about research to their family, friends and community for years to come.

3.3

Four foundational behaviours that make a difference

These are not new tasks, and they don't require extra time or resources. They build on what many NHS research staff are already doing — often without realising its impact.

1. Make space for people to think

It may not be possible to change a busy clinic schedule, but considering the tone of a conversation can change how information is received. Taking a breath, making eye contact, or checking in gently with someone at the start can help them settle. It signals that they are seen as a person, not a process.

2. Share information in everyday language

Most people are not familiar with research terminology, and they shouldn't need to be. A perfect script isn't needed. Plain, warm, everyday language helps people understand what's being asked of them and reduces the worry that something is being hidden or glossed over.

3. Treat questions as part of partnership

When someone brings up concerns, especially about trust, history or previous bad experiences, it isn't a challenge to professionalism. It's a sign they're genuinely considering what this means for them. Listening carefully, acknowledging their feelings, and responding openly can turn hesitancy into understanding. People don't need all the answers, they just need to hear honesty and facts.

4. Affirm the value of participation

For many people, it matters to know that their contribution is meaningful.
A simple, sincere line such as: ***"We want research to reflect everyone, so care can be fair for everyone,"*** helps people see their role in a wider picture of improving health outcomes for their communities.

4

PRINCIPLES FOR WORKING WITH BLACK AFRICAN AND CARIBBEAN COMMUNITIES

Before we get into step-by-step guidance, it helps to hold a few core principles in mind.

Many people of African heritage identify first by their national or regional background rather than solely as Black, for example, the Somali community. Black African and Caribbean communities are not a monolith; they include African communities, Caribbean communities, and people of dual heritage. Using Black African and Caribbean in engagement recognises how people see themselves and how they want to be addressed.

4.1

Work with communities, not simply in them

Real partnership means that communities are not only audiences, but co-shapers of the work.

That includes:

- Involving community partners early, not just at the "promotion" stage.
- Asking, "What matters most to you?" before deciding what should happen.
- Being willing to adapt plans based on the feedback from Black Caribbean and African communities.

4.2
Lead with respect and clarity

People want to play their part in improving health outcomes for Black African and Caribbean communities — but they need to know exactly what they're stepping into.

That means explaining plainly:

- What NIHR IBHO BioResource is, or what the research project you are working on is.
- What taking part actually involves (step by step). Click here to watch our video.
- What happens to people's data – now and in the future.
- What rights participants have: to withdraw or ask questions.

4.3
Share benefits and power

Communities should not feel "used for data".

They should be able to see:

- The difference their participation is making.
- How their feedback shapes the next phase of work.
- Where they can challenge or suggest improvements.

4.4
Stay for the long term

Trust is rarely built through a single event or campaign.

It grows when organisations show up consistently, keep their promises, and stay present even when they are not actively recruiting.

In the rest of this toolkit, we translate these principles into practical steps you can follow.

■5

FROM INTENTION TO ACTION: A STEP-BY-STEP JOURNEY

This section walks through the journey from early planning to long-term relationship-building.

Each of the five stages has two parts:

1. CONTEXT

WHY THIS MATTERS

2. PRACTICAL STEPS

HOW TO DO IT — STEP BY STEP

The later checklists at the end of the toolkit mirror these stages, so can be quickly turned into action plans.

Stage 1:
Understanding your local context and partners

WHY THIS MATTERS

No two places are the same. Black African and Caribbean communities in one area may have different histories, priorities, and trusted spaces than those in another. Before inviting people to take part in research, it's important to understand who is already active locally, what conversations are already happening, and where trust already exists.

HOW TO DO IT — STEP BY STEP

1. Map the community landscape

- Identify local Black African and Caribbean-led or Black African and Caribbean-serving organisations, faith institutions, health advocates, youth groups, and mutual aid or support networks.
- Look for people who are already trusted: community organisers, pastors, imams, barbers, hairdressers, peer supporters, or local health champions.

2. Listen before creating a plan

Arrange informal conversations or short listening sessions with key community partners.

Ask open questions such as:

- "What are the main health concerns or pressures in your community at the moment?"
- "What has your experience been with health services and research so far?"
- "What would make people more likely to engage — or less?"

3. Identify shared priorities

- Look for overlap between local priorities (e.g. diabetes, hypertension, mental health, maternal health) and your area/s of research focus.
- Use that overlap as the basis for collaboration: "We are working on X, which links to what you're already doing on Y."

4. Agree on how to work together

- Be clear about expectations: What can be offered (information, speakers, small grants, training, materials)? What is needed from these community partners (space, outreach, co-design)?
- Discuss how decisions will be made and how feedback will be handled.

This early stage is where the focus moves from "we want to reach Black communities" to "we are working alongside specific people and organisations who are already trusted".

Stage 2:
Planning engagement and events

WHY THIS MATTERS

Events and community sessions are often the first real contact people have with research professionals and/or with NIHR IBHO BioResource. If they feel rushed, confused, or that the interaction is transactional, trust can be damaged before it has a chance to develop. A well-planned session feels like a gathering rather than a lecture: people are welcomed, heard, and given space to think. A new event or session is not always needed. It could be more appropriate to add value to an event that a partner is already running.

HOW TO DO IT – STEP BY STEP

1. Co-design the event format

- Sit down with community partners and ask: "What kind of session would work best here?"
- Consider the audience (age, interests, language needs), timing (evenings, weekends), length of the event (how long can the audience be engaged), and setting (church hall, community centre, school, workplace, online).

2. Plan the flow of the session

A simple structure that works well is:

Arrival and welcome:
Registration, informal conversation, refreshments, music.

Opening:
A welcome from a trusted community host, and a short introduction to the research project.

Story and explanation:
A short talk or story that explains what the research is, why representation matters, and how participation works.

Questions and discussion:
Open time for participants to ask questions, express concerns, or share experiences.

Invitation to participate:
Clear explanation of how to sign up (on the day or later), with no pressure.

Close and next steps:
Summary of key points, outline of what will happen next, and how people will hear back.

3. Make the environment welcoming

- Provide food and drinks — it helps people relax and signals hospitality.
- Consider childcare needs; can a family-friendly set-up be offered?
- Ensure signage is clear so people know where to go.

4. Prepare the team

- Brief everyone on key messages: what the research project is, what participation involves, and what to say about data and consent.
- Talk through difficult questions or past negative experiences that might come up.
- Emphasise the importance of listening without defensiveness.

5. Plan how to capture learning

- Decide in advance how to capture questions, themes, and concerns raised.
- Agree on who will follow up on any issues that need further response.

A community event is not just a “recruitment opportunity”. It is a chance to listen, to build relationships, and to show — through behaviour — that this partnership is worth entering into.

Stage 3:
Talking about the IBHO BioResource or research in clear, honest ways

WHY THIS MATTERS

For many people, “research” and “BioResource” are unfamiliar words. If the explanation is vague or overly technical, people may feel confused or suspicious. If information about data and consent is rushed, they may feel that something important is being hidden.

HOW TO DO IT – STEP BY STEP

1. Use everyday language

- Instead of “cohort”, say “group of people who have agreed to share information to help improve health care.”
- Instead of “genomic data”, say “information from your DNA that helps us understand how illnesses affect different people.”

2. Explain the journey of a participant

Click here to watch our video.

Take people step-by-step through what happens if they say yes:

- What they will be asked to do (for example: give a small blood sample, share some health information, be contacted about future studies).
- How long it will take.
- What will not happen (e.g. “We will not share your personal details with anyone outside the research team without your consent.”).

3. Be upfront about data

- Explain where data is stored, who can access it, and under what conditions.
- Be honest about potential future use but also about safeguards and governance.
- Make it clear that people can withdraw and how they can do that.

4. Make room for "no"

- Say explicitly that it is okay to say "no" or to take time to decide.
- Respect boundaries and avoid any sense of pressure or guilt.

5. Invite questions — and treat them as a gift

- When someone asks a challenging question, thank them. It shows they are engaged.
- Where answers are not known, it's best to say so and commit to coming back with a response at a later time.

The goal is for people to leave thinking: "I still have things to consider, but I understand what this is, and I know how to ask more questions"

Stage 4:
Telling the story — campaigns, publicity and media

WHY THIS MATTERS

Stories, images, and media coverage can either build trust or reinforce distance. Many people still cannot picture what research participation actually looks like. Seeing real people — in familiar settings, engaged in real conversations — helps make the work tangible and relatable.

At the same time, there is a responsibility to ensure that people are represented with dignity and that their consent is central.

HOW TO DO IT - STEP BY STEP

1. Design campaigns with — not just about — the community

- Involve community partners and participants in shaping messages, imagery, and tone early in the process so they know they are part of the creative process from the outset.
- Test early drafts of materials with a small group and ask: “Does this feel like it is speaking to you, or at you?”

2. Prioritise authentic representation

- Show a range of Black African and Caribbean identities: different skin tones, ages, genders, and roles.
- Avoid clichés or one-dimensional portrayals (e.g. only using images of illness or distress).

3. Handle images and stories with care

- Always obtain clear written consent for photos and filming, explaining how the content will be used and where it may appear.
- Offer people a choice: they might be happy for photos to be used locally, but not nationally, or vice versa.

- Give people copies of photos or finished materials where possible, and thank them for their contribution.

4. Engage with the media thoughtfully

- When speaking to journalists, centre community voices and co-created messages rather than technical detail alone.
- Be honest about the history and the work still to be done, while highlighting positive change and partnership.

5. Close the loop

- Share coverage or campaign materials back with partners and participants so they can see how their involvement is reflected.

Good communications are not just about visibility. They are part of the relationship-building process.

Stage 5:
Keeping the promise — sustaining relationships over time

WHY THIS MATTERS

Trust is built not only on what is said at the start, but on what is done afterwards. Communities notice whether promises are kept, whether feedback is acted on, and whether organisations stay in touch beyond a single project or funding cycle.

Sustaining relationships is not about endless activity. It is about consistent, honest contact and a clear sense that the partnership continues to matter.

HOW TO DO IT — STEP BY STEP

1. Plan follow - up from the beginning

- When planning an event or campaign, also plan when and how reporting back will happen.
- Decide what can realistically be shared (e.g. number of sign-ups, changes in approach, emerging findings).

2. Create simple ongoing contact points

- Agree on a named contact person for each community partner.
- Consider a quarterly email, a WhatsApp group, or brief check-ins that keep people updated on progress and new opportunities.

3. Respond to feedback — including criticism

- When concerns are raised, acknowledge them, explain what can be changed, and be honest about what cannot.
- Show, over time, how earlier feedback has led to adjustments in practice.

4. Recognise and value community contributions

- Thank people publicly (with consent) at events, in newsletters, or on social media.
- Where possible, ensure partners are resourced for their time and expertise, not expected to volunteer indefinitely.

5. Look beyond a single project

- **Ask:** “What does a long-term relationship with this community look like?”
- Explore opportunities to co-design future projects, advisory roles, or community-led initiatives linked to research.

Sustaining trust is not about perfection; it is about consistency, openness, and a willingness to keep learning.

6

MAINTAINING STRONG RELATIONSHIPS WITH BLACK AFRICAN AND CARIBBEAN COMMUNITIES

This section brings the relationship-building elements together into one place, so teams can see the full picture of what it means to work in an ongoing, relational way rather than a one-off, transactional way.

Think of the relationship as a loop rather than a line:

Connect

introduced, show up, and listen.

Collaborate

plan and act together.

Communicate

share what happened and what changed.

Continue

stay in touch, adapt, and build on what's been learnt.

6.1

What good relationship-building looks like in practice

- **It is two-way.** This is not only about asking people to take part; it is also about asking, "What do you need from us?"
- **It honours existing work.** This recognises what communities are already doing for their own health and wellbeing, and looks for ways to support or connect to that.
- **It is transparent.** Openness about decisions, constraints, risks, and benefits helps support trust and understanding.
- **It is patient.** It is recognised that not everyone will sign up immediately, and that trust may take time and repeated contact to build.

6.2

Practical habits that help relationships grow

Learning from practice suggests that relationships are more likely to grow and deepen when the people working in health research:

- Are present at community events even when not presenting, creating space to listen, learn, and be present rather than to lead.
- Take care to remember names, faces, and previous conversations, recognising that people notice when they are treated as individuals rather than as "target groups".
- Share opportunities with partners ahead of wider public announcements, signalling respect, trust, and priority.
- Keep commitments small and realistic, and follow through on them, recognising that it is often better to promise less and deliver consistently than to over-promise and disappoint.

The checklists at the end of this toolkit translate these shared learning points into practical actions that can be built into work plans and adapted to different contexts.

■7

NEXT STEPS FOR PARTNERS

As this toolkit is used, it may be helpful to:

1.

Focus on the sections most relevant to the role or project at hand.

2.

The checklists can be used as planning tools with teams and community partners.

3.

Reflect after each activity:
What worked well?
What felt uncomfortable?
What was learnt about trust?

4.

Share learning back with the wider NIHR IBHO BioResource team so that good practice can spread.

Every conversation, no matter how small, is an opportunity to rebuild trust and move towards fairer health outcomes for Black African and Caribbean communities.

Additionally, any feedback provided about how the toolkit has been used will enable us to improve it over time.

8

PRACTICAL CHECKLISTS

These checklists are working tools. The sections can be adapted, expanded, or simplified to suit different local contexts. The core aim remains the same: to share learning and encourage informed, respectful, and genuinely partnership-led approaches to engaging Black African and Caribbean communities, so that health research better reflects everyone. Because when everyone is seen, everyone is cared for.

CHECKLIST

8.1

Planning an event

1. Before the event

- Have local Black African and Caribbean partners or leaders been involved in early conversations about the event idea?
- Has the purpose of the event been agreed (for example, information-sharing, listening, sign-up, or a mix)?
- Is the format being co-designed with community partners?
- Has a venue been chosen that is familiar, accessible, and trusted by the community?
- Have the date and time been considered in relation to work patterns, faith commitments, and caring responsibilities?
- Has childcare or the need for family-friendly arrangements been considered?
- Are food and refreshments being provided?
- Has it been agreed who will host the event (ideally a trusted community voice) and who will speak on behalf of the research project?

- Have clear, plain-English explanations of your research project and organisation been prepared that also detail what participation involves?
- Are materials ready (for example, sign-up forms, consent forms, information sheets, and feedback forms)?
- Has planning taken place for how photos or videos will be captured and which consent forms are required?
- Have the person/people who will be using the photos and videos, and who will obtain consent, been determined?
- Has a clear approach been agreed for capturing questions, concerns, and feedback during the event?

2. During the event

- Are attendees welcomed warmly on arrival and supported to find their way?
- Does the opening acknowledge the history of mistrust and explain why this event may feel different?
- Is sufficient time built in for questions and open discussion, rather than presentations alone?
- Are questions being answered honestly and without pressure?
- Are sign-up options explained clearly, including the option to decide later or not take part?

3. After the event

- Have partners and attendees been thanked, either in person or through follow-up communication?
- Have key questions and concerns been captured, with clarity on who is responsible for responding?
- Has there been agreement on how and when a summary of “what we heard and what we’re doing next” will be shared?
- Has internal reflection taken place on what worked well and what could be approached differently next time?
- Have reflections, learning, and feedback been shared back with community partners?
- How will the reflections, feedback and learnings be used to inform next steps?

CHECKLIST

8.2

Creating a campaign/publicity materials

1. Before creating materials

- Have Black African and Caribbean partners or participants been involved in shaping the key messages?
- Is there a clear understanding of the main concerns and motivations of the audiences being reached?
- Has the specific action being invited been clarified (for example, attending an event, signing up, or learning more)?

2. When drafting content

- Is the language clear, conversational, and free of jargon?
- Does the content explain why representation matters, not only what action is being encouraged?
- Is there a clear explanation of what the research project and organisation and what participation involves?
- Are common questions (such as data use, consent, and time commitment) addressed upfront?

3. Imagery and representation

- Do images reflect the diversity within Black African and Caribbean communities (including skin tones, ages, genders, and roles)?
- Is care being taken to avoid stereotypes or tokenistic imagery?
- Has consent been secured for all images, with clarity about where and how they will be used?

4. Testing and finalising

- Have draft materials been tested with a small group of community members and partners?
- Have reflective questions been explored, such as: “Does this feel like it’s speaking to you?” and “What feels off?”
- Have materials been adjusted in response to feedback?
- Is there clarity about how and where materials will be shared (for example, online, in print, on social media, through local radio, or in faith spaces)?

CHECKLIST

8.3

Working with the media

1. Preparation

- Is there clarity about key messages, particularly around representation and trust?
- Have community partners or participants (where they wish to be involved) been identified who could speak for your project?
- Are those partners fully briefed and comfortable with the messages being shared?
- Has appropriate consent been obtained for the use of recordings, videos, photographs, or other media?

2. During media engagement

- Have key spokespeople been provided with briefings and media training so they can feel confident answering difficult questions?
- Is communication taking place in plain language, avoiding jargon or overly technical terms?
- Is there openness about historical and present-day inequalities, alongside highlighting positive change and partnership?
- Is due credit being given to community partners?

3. Safeguarding and consent

- Do all interviewees understand where and how content will be used?
- Do interviewees have the option to review quotes or recordings where appropriate? If not, have they been clearly informed of this?
- Have any potential risks for individuals who may be identifiable in media coverage been considered and discussed with them?

4. Follow-up

- Have links or copies of coverage been shared with community partners and participants?
- Have thanks been shared with everyone who contributed?
- Has there been reflection on how the coverage was received locally, and learning captured about what might be approached differently next time?
- Have the findings been shared with partners to maintain a two-way dialogue, build on shared learning and inform improvements or changes for future activity?

CHECKLIST

8.4

Building and sustaining relationships with Black African and Caribbean communities

1. Starting the relationship

- Have key Black African and Caribbean organisations, leaders, and informal influencers been identified locally?
- Has engagement begun with openness, creating space to understand community priorities before presenting plans?
- Have the history and present-day experiences that may shape trust been acknowledged?

2. Working together

- Are activities and materials being co-designed, rather than shared as finished plans?
- Is there scope to explore how health research teams can support what communities or partners are already doing, rather than working separately, including conversations about capacity, funding, or resources where appropriate?
- Are roles, expectations, and resources (including payment where relevant) clear on both sides?
- Is there a shared understanding of what success looks like — for both the staff on the research project and community partners?

3. Staying in touch

- Is there a named contact person for each partner, with up-to-date details?
- Is there a simple and realistic rhythm of communication (for example, quarterly updates or check-ins after key milestones)?
- Is there a consistent approach to sharing back what has changed or progressed as a result of community involvement?

Responding and adapting

- Is there an easy and accessible way for partners to raise concerns or suggestions?
- When feedback is shared, is it responded to promptly and honestly?
- Are there clear examples of where community input has led to changes in approach?

Looking to the future

- Are future opportunities beyond the current project or campaign being discussed?
- Is there exploration of roles for community members in advisory or co-leadership positions?
- Is learning being captured in ways that can be shared across teams and regions?

■ 9

LIST OF ASSETS

We have provided a number of print-ready assets for sites or centres delivering the Improving Black Health Outcomes programme that can be used or tailored as required as part of local campaigns and events. Please do reach out if you'd like to access them.

- Posters
- Postcards
- Lifecycle video
- Hero videos
- Social media graphics

Get in touch

Website	https://bit.ly/ibhoallinfocus
Contact	ibho@bioresource.nihr.ac.uk

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