Volunteer member information pack:

# Member – Confidentiality Advisory Group (CAG)

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| Closing date | Friday 02 February 2018 |
| Closing time | 2pm |
| Submit electronically (*preferred*) to: | [HRA.CAG@nhs.net](mailto:HRA.CAG@nhs.net) |
| Submit hard copy to | Confidentiality Advice TeamHealth Research Authority Skipton House  80 London Road  London  SE1 6LH |
| Electronic and paper applications received after this time will not be considered further | |
| Shortlisting confirmation (by email) | **26 February 2018** |
| Interview date | Early March 2018 (date tbc) |

**Background**

**THE HEALTH RESEARCH AUTHORITY (HRA)**

The HRA is a Non Departmental Public Body with the remit to protect and promote the interests of patients and the public in health and social care research. We do this by supporting and promoting a robust and efficient regulatory and governance framework in the UK. We provide the Research Ethics Service (RES), Confidentiality Advice function, assessments and assurances on behalf of the NHS, and learning, guidance and advice for the research community. Our ambition is to make the UK a great place to do research, where more money invested in research goes into carrying out relevant, good quality research.

Our purpose is to ensure that research involving NHS patients and members of the public is approved through a proportionate and robust system, that they are provided with the information they need to help them decide whether they wish to take part and that their opportunity to do so is maximised by simplifying the processes by which high quality research is assessed. We have already delivered significant improvements by centralising and simplifying the approval of research in the NHS in England, and are undertaking a range of significant programmes to deliver further improvements.

To achieve our purpose, we work with all relevant partners to help create an environment where:

* greater numbers of patients and the public can and do take part in health research, and continue to feel safe when they do;
* applying to do research is simpler, and getting a decision is quicker;
* researchers find it easier to do high-quality, ethical research;
* the NHS appreciates how health research benefits patients and staff;
* industry sees the UK as a great place to do health research;
* more money from charities and other research funders goes into carrying out research, and less into getting through unnecessary hoops before it starts;
* clinical trials are registered and research results get published.

The HRA has a number of functions. We:

* are the Appointing Authority for Research Ethics Committees in England and provide the RES;
* by agreement with the Devolved Administrations, we support a UK-wide system for ethical review in the UK;
* appoint the Confidentiality Advisory Group; an expert group which provides independent advice to the HRA regarding the appropriate use of confidential patient information without consent in the NHS for research, and to the Secretary of State for Health for other purposes, such as commissioning health services;
* provide HRA Approval for the NHS, including assessments and coordination of technical assurances by staff, as part of a compatible system across the UK;
* work in partnership to coordinate our activity with other organisations regulating and governing research, including the Medicines and Healthcare products Regulatory Agency (MHRA), Human Tissue Authority (HTA), Human Fertilisation and Embryology Authority (HFEA), National Institute for Health Research (NIHR) and Administration of Radioactive Substances Advisory Committee (ARSAC);
* provide advice and support through our advice service, published guidance, information and training programmes;
* provide the Integrated Research Application System (IRAS), through which all applications for regulation and governance of health research are made in the UK, and have agreed plans to provide a unified approval process from the IRAS platform;
* have an on-going programme of work to shape effective national roles for the HRA, within our remit to provide a unified approval process and to promote proportionate standards for compliance and inspection.

The HRA relies on the members who serve on its committees, who give their time freely to provide a robust and independent review of research proposals.

**Role of the Confidentiality Advisory Group**

The CAG is an advisory committee of the Health Research Authority and delivers two important roles set out in statute:

1. To consider applications to access relevant information without consent under the NHS Act 2006 and the Health Service (Control of Patient Information Regulations) 2002

Access to patient and service user information without consent is a privilege and the CAG takes its responsibilities seriously. Applications are varied, relate to both research and non-research activities and are received from academic, NHS, local government, government bodies and national organisations. The CAG considers these applications and provides its independent advice to the decision-makers: the Secretary of State for Health (via the Department of Health) and the Health Research Authority.

Where support is provided, data can be disclosed to specified persons without a breach of the common law duty of confidentiality. The CAG acts as an important and independent safeguard, as part of a broader system, to help improve public confidence in the appropriate use of information.

1. To provide advice to NHS Digital on aspects related to its data dissemination, under the Care Act 2014.

This is a developing role and one that takes place in collaboration with NHS Digital.

**Qualities required for the role**

Membership of the CAG is drawn from a range of backgrounds however we are looking for people who are passionate and committed to the role of the CAG, who are able to work effectively and collaboratively, support the function it delivers and are able to deliver a balanced recommendation. The CAG would welcome applications from anyone who meets the criteria including members of the public, representatives of patients, members of consumer groups, health care professions, professional regulatory bodies and academic/ research institutions.

The successful applicants will already have, or be willing to develop, an understanding of research and on-research activities, application of the common law duty of confidentiality, patient consent and use of the Health Service (C0ntrol of Patient Information) Regulations 2002 (‘section 251 support’); knowledge of information governance and research processes and an understanding of the current issues currently impacting on use of information within the NHS and other sectors including social care.

The CAG will be particularly interested in applicants who can demonstrate expertise in the following areas:

* Independent lay voice
* Practical experience gained within social care and/or local authorities with understanding of issues around integrated care and research
* Clinical and health research methodology expertise gained through experience
* Commissioning
* Practising clinicians in hospital and general practice, voluntary and third sector
* Experience in dealing with mental capacity issues
* Experience in dealing with mental health issues
* Expertise and experience in Information Governance at the appropriate level
* The ability to apply legal reasoning to practical scenarios within advice recommendations
* Senior level experience gained within public health
* Epidemiology expertise
* Relevant legal knowledge and experience
* Clinical and health research methodology expertise
* Experience working in private/commercial sector
* Experience in the issues around use of GP data
* Research ethics experience

To help you decide if you wish to apply for appointment for the role of CAG member, we have listed below the main responsibilities, and the criteria that will be applied when assessing candidates. To be considered, you must be able to demonstrate within the application form that you have the qualities, skills and experience to meet the criteria.

**Role Description**

The main responsibilities of CAG members are:

* To consider a diverse range of applications from a variety of organisations (research institutions, government bodies, commercial bodies and health and social care organisations) on the application of the Health Service (Control of Patient Information) Regulations 2002, and to provide advice to the Secretary of State for Health and the Health Research Authority on whether applications should be approved, and if so, any relevant conditions of approval.
* Provide robust advice to NHS Digital upon request on relevant issues related to dissemination; ensuring that the advice provided is within the framework of CAG considerations.
* To provide advice (by MoU agreement) to the Human Fertilisation & Embryology Authority on access to their research register
* To understand and apply the legal framework, good practice guidance, ethical, and technical aspects of consent and confidentiality to the work of the Group, so that advice provided is robust and transparent.
* To use expertise to enable the CAG to provide sound advice on considered applications
* To raise relevant information governance and other issues which arise as a result of CAG exercising its advisory functions with respect to the Health Service (Control of Patient Information) Regulations 2002.
* To ensure the views of relevant stakeholders (including patients) are included in the considerations of CAG
* To work with applicants and the secretariat, where applicable, to aid in resubmissions and bringing own expertise to applications
* To be available to attend meetings, provide advice on scheduled proportionate review applications and amendments outside of meetings, as well as away days and training activities.
* To support the CAG through working groups to continue to develop its Improvement programme
* To proactively maintain and develop the knowledge necessary to fulfil the role e.g. through attending education and training sessions

**Member specification**

* Skills to understand and analyse applications for access to confidential data from medical researchers, NHS and commercial bodies, and evaluate the governance arrangements, public interest and potential harms to assist the Group in reaching a considered recommendation at each meeting.
* Ability to synthesise information and present a relevant, concise and evidenced recommendation to the group orally and in writing.
* Ability to consider and balance a range of views of members and have the skills to re-evaluate one’s argument, in the light of other persuasive views. and fully support consensual decision making
* Good understanding of standards in relation to information governance, confidentiality and consent and the ability to apply relevant principles to individual situations
* Commitment to facilitating appropriate activities, promoting patient autonomy, information communication practices, and understanding the sensitivities about using confidential patient information without consent to support research or other activities
* Commitment to developing own understanding of the needs of researchers, and research regulation, including research ethics committees, HRA assessors and other approval bodies, together with other non-research uses of patient information, such as national audit and commissioning.
* Good understanding of, or willingness to rapidly learn, the legal basis of the work of the Group (this includes s251 of the NHS Act 2006 and Health Service (Control of Patient Information) Regulations 2002, Human Rights Act 1998, and information governance in relation to the use of health records
* Experience of committee-type work and effective contribution within this environment.
* Commitment and availability to attend CAG meetings and review proportionate review applications outside the full meeting schedule, and to be aware of time required to develop own learning.
* Interest in understanding and knowledge of the way the health and social care system works, the information challenges and the broader political environment
* Demonstrate and adhere to the Nolan Principles of Public Life

**Support for the role**

The Health Research Authority values the important contribution the role of CAG volunteer members through their review of applications and in supporting the members in delivering a credible advisory function. The following are provided to support the member role:

* Away day. The CAG holds two away days per year that provide the opportunity for issues of particular note and relevance to be debated in detail.
* Education items. The CAG aims to have education sessions every two months on specific topics to help develop member knowledge and understanding.
* Confidentiality Advice Team. This team provides a secretariat function and maintains the day to day operations of the CAG under the COPI Regulation function and liaises with applicants and other key stakeholders on behalf of the CAG so the member role is focused on priority matters. They produce the advice recommendations based upon the CAG discussions and liaise with the decision-makers. The Head of Service provides more direct support to the Chair and officials in relation to the discharge of the function to advise NHS Digital and through advising on more complex matters, broader policy contexts and legal frameworks where applicable, with support from the HRA where appropriate.

**Some questions you may have**

Please note, this is a voluntary position and as such does not accrue employment rights under employment legislation.

**What kind of person would make a good member?**

Access to patient information without consent is a privilege and individual members must be able to work respectfully and collaboratively, as part of a group, to seek to reach an effective advice recommendation; an understanding of the practical issues around implementation will be critical to ensure that the advice provided to the decision-makers is robust.

You would have a very real interest in promoting and protecting patient autonomy and confidentiality, and also in supporting research and other appropriate uses of confidential patient information.

You will need to be respectful of others and confident about expressing and supporting your own opinions and most importantly, be able to re-evaluate one’s argument in light of other perspectives in order to support consensual advice provision.

As this is a unique role you must be comfortable in accepting that due to the nature of the areas considered, you will be exposed to new issues and be expected to develop your understanding of the general issues considered by the CAG. All members bring their own experience and knowledge however this must be framed within the current legal framework. This knowledge will be provided via induction to support members as they take up the role.

Interested candidates should consider whether they have the time required to fulfil the role; further information is below regarding the time commitment. All members are expected to be familiar with using email systems

**What sort of experience should I have?**

CAG membership consists of a mix of professional and lay members. Lay members come from all walks of life and bring differing experience to committees. It is necessary to have been involved in some kind of committee-type work before, although you may not have been a member of a formal committee. You should however have an understanding of how organisations work and in particular of how meetings are run through previous experience, for example, through experience gained through involvement with community groups, schools’ representative bodies, voluntary organisations or charities, business, or industry.

**What would I be expected to do?**

You would work collaboratively with the rest of the group in person or via email using your skills, knowledge and experience to review applications, amendments or annual reviews and generate evidenced advice about whether applications to access patient information without consent should or should not be approved, and to identify where improvements can be made to applications to enable the Group to recommend approval where appropriate. Applications will be considered either face to face or via email so technological competence with email and Microsoft Word is essential.

Following an induction period, you will typically be allocated an application to lead upon and prior to the meeting you would be expected to read the agenda papers and be prepared to present and discuss these concisely. At the meetings, the proposals will be discussed, and for contentious applications it may be possible to ask questions directly to the applicants themselves, before a final advice recommendation is given by the Group.

**How much time is involved?**

Meetings are held on a monthly basis and, depending on the volume of business, will usually be of one-day duration (10.30 – 4.30). Each meeting would typically require three to four hours preparatory reading although it is difficult to be precise as some applications are more complex than others and can take longer to review as knowledge is developed. Members will be allocated a specific number of applications to lead on and will be a reviewer for a specified number of applications.

Members can also expect to review approximately 1 or 2 proportionate review applications or amendments per month, depending on the nature of the application and member expertise.

Applicants are advised that as knowledge and confidence in the area is developed that it will take longer to review applications in detail when initially taking up the role, although as familiarity with the issues increases this time should decrease. It is important to recognise the time commitment required to effectively fulfil the responsibilities of the role.

The CAG has also been given a new statutory function to advise NHS Digital. New members can therefore expect elements of change as the this part of the CAG remit develops and comes into effect, and should therefore be comfortable operating within this environment.

**Where will meetings be held?**

Meetings will be typically based in HRA offices in Manchester or London but can also be regionally based. Members are expected to be present for at least two thirds of all meetings as a condition of membership. Members typically attend no less than 9 meetings per year as knowledge development is cumulative.

Due to the expertise that members bring, it will not be possible to send a deputy in a member’s place.

Precedent-set reviews and amendment consideration will take place via email and members will be expected to respond within key performance indicator timescales.

**Who else is on the Confidentiality Advisory Group?**

Our membership is taken from people in all walks of life who are representative of the community and general population, whether employed, unemployed or retired. There are also legal specialists, clinicians, researchers and public health specialists on the group.

All our members are passionate about the role of the CAG and respect the function it delivers.

**For lay members – will I be able to continue with my current job?**

This will clearly depend upon your current employer’s policy on such appointments (e.g. for employees who are also JPs or who serve on parole boards and school governors). You must bear in mind that meetings are held during the working day.

If you are in receipt of certain state benefits you may wish to obtain independent advice about whether your planned involvement in our work affects your continued entitlement. HRA wishes to ensure that people who must keep within benefit conditions that may apply to paid or voluntary participation are not prevented from participating in our work. We may be able to adjust our offer to you, to comply with your benefit conditions if requested.

**For expert members – will my organisation support my attendance at the meetings?**

CAG meetings are held during the working day. Some employers may allow you time to attend the meetings but you should check this with your line manager or employing authority. Most organisations appreciate the valuable work of national committees such as CAG. Membership is often recognised in Consultant Job Plans.

**What is my legal position?**

Any member acting responsibly within the committee is ‘indemnified’ by the Health Research Authority. That is, the Health Research Authority will protect members against civil action that might arise from the business of the committee. This is with the provisos that the lay member informs the Health Research Authority and co-operates with them in respect of any claim made against them, and has not acted in bad faith, wilfully defaulted on their responsibilities or been grossly negligent.

**How long would I serve as a member?**

A term of office will be generally five years although this will be dependent on recruitment cycles and will be agreed upon appointment. Terms of appointment may be renewed, but normally not more than two terms of office are served consecutively.

**Will training be provided?**

Training is provided for all members in the basic framework of the Regulations during the induction session however regular attendance is seen to be the best way to develop knowledge and understand how it is applied. New members can be allocated a mentor to assist with initial queries.

New members will be expected to attend an induction in April 2018. New members will be allocated an existing member to act as a buddy and to facilitate the transition. The CAG induction will allow the opportunity for new members to understand the legal framework, the CAG role and evolving responsibilities and provide opportunity for any queries to be resolved at an early stage.

You would be expected to attend this initial induction event in order to undertake your member role and then at least one training event per year in accordance with HRA member requirements.

**Will I be able to claim expenses?**

Any travel costs or other agreed expenses incurred undertaking CAG duties will be reimbursed in accordance with HRA policies; the HRA will typically book all travel and accommodation requirements. All payments are made by BACs and in line with the HRA Expenses Policy.

**Who would I be representing?**

Members of CAG are not appointed to represent any particular interest group.

Members are drawn from a variety of groups to give as wide a perspective as possible. However lay member viewpoints will be important in supporting the interests of the patient. It is hoped that the lay member will bring their own valuable perspective to the Group deliberations through a variety of experiences, contacts and networks, and be able to reflect current public views and concerns. You might like to think about the lay member role as the person who consciously considers how any decisions might appear or feel to a patient. This is clearly not the sole prerogative of the lay member because other people within the Group will undoubtedly have their own sensitivities and perceptions.

**Does CAG take decisions?**

No. the CAG is an advisory committee. It provides formal independent advice to the decision-makers.

**Who can I discuss this with in greater detail?**

In order to ensure that we can effectively respond to your requests please email [HRA.CAG@nhs.net](mailto:HRA.CAG@nhs.net) with a brief description of your request e.g. whether it is about the role itself, its terms and conditions or the recruitment process. This way we can make sure we put you in touch with the right person.

**How to apply**

To apply for this role please complete the Application form, enclosing a copy of your CV and the Equal Opportunities Monitoring Form, to be submitted no later than 2pm on Friday 02 Feb 2018. All documents and questions must be fully completed to enable the application to progress to shortlisting stage. Applications received after this date and time will not be considered further.

All completed documents should be e-mailed to [HRA.CAG@nhs.net](mailto:HRA.CAG@nhs.net) or sent to:

Simon Depledge (CAG)

Health Research Authority

Skipton House

80 London Road

London

SE1 6LH

**If you require a hard copy of the application form to be sent to you, please contact HRA.CAG@nhs.net**

**Once we receive your application**

After the closing date for applications:

1. We will acknowledge receipt of your application (typically by email) and check it for completeness and eligibility; incomplete forms will not be considered further so interested candidates must make sure all details have been provided.
2. The interview panel will rely on only the information you provide on your application form and CV to assess whether you have the experience required at the appropriate level.
3. Please ensure that you provide written evidence to support how you meet all of the relevant criteria, which are identified in the role description and qualities required for the role
4. Successful candidates will be contacted by email and invited for interview to take place at a Health Research Authority office (typically London-based)
5. If a large number of applications are received we will be unable to provide feedback to those not shortlisted to interview.
6. Where a candidate is unable to attend an interview on the set date then an alternative date may offered at the discretion of the interview panel, noting opportunities for this may be limited.
7. The core interview panel will consist of:
   1. CAG Chair
   2. CAG vice Chair / alternative vice-Chair / CAG members
   3. HRA Head of Confidentiality Advice Service

There may also be further stakeholder engagement in the process

**The interview**

If invited to interview, the following will apply:

1. You will be asked to review a sample application, provided on the day, in approximately 40 minutes and be prepared to deliver a 5 minute summary on the application, your view of the core issues and provide a recommendation.
2. The panel will question you around your review of the application
3. There will be an interview of approximately 40 minutes
4. Please allow approximately 90 minutes for the entire interview and test
5. If you are successful, you will receive a letter from the HRA appointing you as a member of the CAG
6. If you are unsuccessful following interview, you will be notified by the Health Research Authority.