Policy for Working in Partnership with Patient Advocates

Welcome message

Patient engagement is important. It is important to the Healthcare Quality Improvement Partnership (HQIP), to patients and to healthcare providers - but it is also crucial for healthcare services. Through working closely with patients and communities, we can understand their priorities and concerns to develop services that truly meet those needs.

HQIP is proud to work in partnership with patient advocates in guiding and co-creating our work - from programme design through to outputs. This policy has been developed to support our patient advocates, including members of the HQIP Service User Network (SUN) and the National Obesity Audit User Panel and to guide all HQIP staff in this work.

It has been co-produced with four SUN members and reviewed by a further six SUN members before publication. We are grateful to all our members for contributing their time and expertise and thank them for their support in its development.

We hope you (patient advocates) find the policy useful, and that it provides you with helpful information about getting involved with HQIP.

Contents

1. Glossary

HQIP – Healthcare Quality Improvement Partnership

SUN – Service User Network

NCAPOP – National Clinical Audit and Patient Outcomes Programme

PPI – Patient and Public Involvement

DARG – Data Access Request Group

IAG – Independent Advisory Group

“Patient advocates” refers to everyone who is involved in HQIP work as members of the public, patients, carers, service users and parents. This list is not exhaustive.

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2. Policy Statement

This policy outlines how patient advocates (also referred to as SUN members, User Panel members, public members, patients, carers, people with lived experience, and service users), are supported in collaborative work with HQIP. It includes procedures, expectations, and payment for involvement fees.

This does not apply to voluntary sector organisations – arrangements will be made separately with organisations when partnering with HQIP to support people and community engagement.

Engagement with patient advocates can take place in various ways, and HQIP is committed to involving the public in most areas of our work. While the level and type of involvement may vary, dependent on funding, HQIP ensures that a patient perspective is included in all projects.

Patients and the public are at the heart of HQIP's work and a core value is to hear and consider the patient perspective. As commissioners of clinical audits and outcome review programmes, HQIP sets expectations for the organisations (providers) managing those programmes to engage with patient advocates and ensure continuous engagement throughout the project cycle.

3. Introduction

The Healthcare Quality Improvement Partnership (HQIP) is an independent organisation established to promote quality in healthcare and, in particular, to increase the impact that clinical audit has on healthcare quality improvement. For more information see here - https://www.hqip.org.uk/about-us/

HQIP’s approach to engaging with patient advocates is set out in an overarching strategy, reviewed every three years with SUN members. This policy outlines the framework for patient advocates who engage with HQIP in various capacities, including:

- **Commissioning for the NCAPOP Programme**: Sharing views and lived experiences to influence the development of specifications for audit or outcome review programmes.
- **Project Involvement**: Participating in the development of project outputs by providing insights from a patient advocate’s perspective.
- **Ad hoc focus groups**: Providing insight from a public perspective to support HQIP work.

- **Advisory/committee group membership**: Participating in regular meetings and overseeing applications or project outputs (e.g. Independent Advisory Groups or Data Access Request Group).

HQIP's Head of Patient and Carer Engagement (referred to in this document as the Engagement Lead), is the main point of contact for all engagement activities. The Engagement Lead will facilitate and manage the engagement process with patient advocates, SUN members, and User Panel members.

As a fully remote organisation, HQIP conducts all core business projects and meetings virtually. While funders' requirements may sometimes limit flexibility in engagement methods, HQIP strives to accommodate patient advocates' preferences/needs and to facilitate inclusive engagement.

In instances of new funding or business opportunities, HQIP aims to involve communities that may be digitally excluded and actively seeks participation from individuals experiencing health inequalities and poor health outcomes. An example about our engagement with marginalised communities can be found here – Listening to marginalised voices in maternity care.

HQIP will be transparent about project remits and limitations, setting clear expectations for patient advocates regarding involvement. This policy aims to provide a clear understanding of what patient advocates can expect when working with HQIP.

4. Activity-Based Payment for Involvement Policy

The activity-based involvement fee table is available below:

**Please note that payment is calculated by the type of activity, irrespective of duration of activity.

Activity and Tasks **	**Fee £**
Resource Development	
Review and comment	15.00
Co-draft and design	30.00
Attend meeting - prep and discussion	40.00
Lead draft of resource	100.00
Write own perspective e.g. case study	50.00
Focus Group (to learn patient perspective)	
Prep and attendance	40.00
Attendance only	25.00
Events	
Attendance only	30.00
Prep and contribute	45.00
Speaking (prep and present)	100.00
Clinical Audit Awareness Week (annual campaign)	
Judging Audit Hero Awards - reading, scoring, meeting attendance	100.00
Project Work	
Review and comment on papers	30.00
Meeting attendance preparation and discussion	40.00
Co-design and co-produce	60.00
Interview Panel (depends on number of applicants)	
Reviewing applications	60.00 – 80.00
Preparation time	30.00 – 40.00
Interview meetings	60.00 – 80.00
Data Access Review Group (DARG) members	
Reading applications before meetings	45.00
DARG meeting attendance	30.00
DARG training	30.00
DARG support meetings	15.00

Claiming payments

Please note the following regarding payment claims:

- Fees for each activity will be communicated beforehand. Any additional expenses must receive agreement prior to the activity from the HQIP Engagement Lead.
- Payment claim forms (an excel spreadsheet) will be sent from the Engagement Lead by email after the activity.
- Support from the Engagement Lead is available to those who need help completing the form.
- Payments are made via bank transfer. Amazon or One 4 All voucher payments might be available in some circumstances.
- Payments can only be made to bank accounts in the participant's name and participants are responsible for providing the correct bank information.
- Should they wish, patient advocates can choose not to claim or accept a reduced amount.
- Claims must be submitted within two months of the activity and payment can be expected within two weeks.

It is essential to adhere to these guidelines to ensure timely processing of payments incurred during engagement activities with HQIP.

Disclaimers

Any income that patient advocates receive may be liable for income tax and members are responsible for declaring any taxable income and for settling any tax liabilities which may arise. For those in receipt of welfare benefits, please seek advice from Citizens Advice regarding how payments may impact your benefits. HQIP cannot take responsibility for any declarations required.

Members with questions about tax can contact HMRC:
https://www.gov.uk/government/organisations/hm-revenue-customs/contact/income-tax-enquiries-for-individuals-pensioners-and-employees
Phone number: 0300 200 300

HQIP reserves the right to adjust payment if you are unable to fully engage as expected. We expect full engagement during meetings, either on camera or via chat, for the entire duration. Should there be difficulty in meeting these expectations, this may result in withholding or withdrawing payment.
Reasonable adjustments can be discussed and arranged with the Engagement Lead.

Main Contact
Any questions regarding payment claims and expenses, please contact the Engagement Lead: Kim.Rezel@hqip.org.uk

5. Important Documents

To ensure comprehensive compliance and understanding of this policy, it must be read in conjunction with the HQIP Code of Conduct, which was co-produced with SUN members:

Code of Conduct

- **Respect everyone's right to contribute, individual differences and opinions – this applies to contributions made at meetings and outside of meetings (e.g. by email)**
- **Respect each member's privacy, safeguarding information and contact details.**
- **Prepare for meetings by reading materials sent in advance and offering your feedback.**
- **Prepare to actively contribute to meetings by giving considered feedback and opinions.**
- **Attend meetings with the intention of being focused and helpful.**
- **Ask for information if you are not sure what to do or say.**
- **Treat all information shared about HQIP, the project, and from all participants, as confidential.**

A breach of the Code of Conduct may be addressed through the Complaints and Grievance Procedures detailed in section 8.

Other documents that might be shared with patient advocates during their involvement are listed below:

Service User Network sign-up form

A form that patient advocates complete to join the SUN. It asks questions about experience, interests, and demographics. This is to enable us to target engagement opportunities and ensure diversity during involvement. Completed forms are sent to the Engagement Lead to add to the database to start receiving SUN newsletters with HQIP updates and opportunities.

General Public Involvement Agreement

A document that patient advocates are asked to sign should they join a project group or committee, such as the Obesity Project User Panel or the Data Access Request Group. It sets out the group purpose, expectations, activities, and payment.

Payment Claim form

The claim form is an excel spreadsheet sent to patient advocates after an activity. Patient advocates complete this by adding their details and the details of the activity with the formerly agreed fees. These are all processed by the Engagement Lead before being dealt with by the Finance team.

Declaration of Interest form (DOI)

Certain activities, committees and groups will require patient advocates to complete the DOI before participation. All who complete the form are expected to list any paid or voluntary roles that bear any relevance to the activity. This is of vital importance to ensure the credibility of our work and to avoid any conflicts of interest. Please also see the Process for declaring interests and dealing with conflicts of interest document on our website.

Confidentiality form

This form is required if you are involved in looking at documents that are not yet published or are under embargo. An example of this is when SUN members are on the judging panels for the Audit Heroes awards for Clinical Audit Awareness Week.

Equity, Diversity and Inclusion statement

This statement expresses HQIP’s commitment to EDI and extends to all staff and stakeholders.

6. Safeguarding Information

How do we keep your personal information safe?

HQIP is committed to safeguarding the personal information of all patient advocates. Personal information from forms completed by SUN or User Panel members is stored in secure and confidential folders on the HQIP drives. Access to these folders is restricted to a limited number of staff members on a need-to-know basis, including the Head of Patient and Carer Engagement, the Director of Operations - Corporate Services, and the Chief Executive Officer.

Once members step down from any groups, their information is deleted from the system. For patient advocates not in the SUN/User Panel, only their email details are kept on file. Contact details and financial information from payment claim forms is shared with the HQIP Finance team and stored in secure folders accessed by authorised personnel only.

Important note: HQIP typically involves people who are over 18 years old; we actively engage parents, carers, and young people. However, special considerations will be made around safeguarding when engaging with children.

How do we manage your personal information during engagement activities?

Open sessions are recorded unless attendees object to this. Any personal information shared during or outside the sessions is only used by a limited number of people at HQIP (such as the Engagement Lead) solely for the purposes of the engagement activity.

Email addresses will only be used in group emails with other patient advocates and HQIP staff, once consent has been received.

Attendees' personal data is not shared with any third parties without your consent. We may need to share some of your information if required by law, for payment of the involvement fees or where needed to ensure appropriate adjustments are made to accommodate your personal needs or preferences.

More information about how your personal data is used and protected can be found in Privacy Notice – HQIP.

Any data protection queries can be directed to Data.Protection@hqip.org.uk.

How do we keep you safe in engagement activities?

Before any open session, the code of conduct is shared and must be followed by all attendees. If the code of conduct is breached, the individual(s) involved will be contacted separately to address the issue.

What should you expect from patient engagement?

SUN members receive regular newsletters with HQIP updates and information about upcoming opportunities for engagement.

User Panel (obesity project) members, receive emails about the obesity related work and engagement opportunities.

Condition-specific patient advocates will be identified through the SUN newsletter and through relevant charities.

HQIP highly values the contributions of all patient advocates and acknowledges their involvement in our work. Members can expect to be paid based on an activity-based involvement fee. For more extensive work where members join a project team or a long-standing group, expectations for both HQIP and members will be detailed in a Public Involvement Agreement and/or the Terms of Reference.

During engagement activities, patient advocates can expect the following:

Upfront Information

- An email will be sent to those interested in any engagement activity with more detail about the opportunity including the involvement fees to expect.
- Any papers attached to the activity will be provided at least one week beforehand.
- Joining links for the meeting will be shared ahead of time.
- Payment claim forms will be shared within two days after the engagement activity.

Support and Accessibility

- Support will be available through 1:1 phone/video calls. This could include assistance with using Zoom or Teams; assistance in completing payment claim forms; help in understanding upfront information.
- Virtual meetings can be accessed by phone for those without access to Wi-Fi.
- Where requested, information can be formatted in a more accessible way such as bigger fonts where possible.
- Pre and Post Support: This is available as and when required in terms of one-to-one discussion about the engagement activity.

Contact Details

Contact details will only be shared beyond the main contact under the following circumstances:

- For Payment: Shared with the Finance team securely.
- Email Addresses: Shared only if agreed upon by the patient advocate.

7. Summary of Values

During engagement activities, patient advocates can expect the following from HQIP:

Summary of Values

- **Etiquette at Meetings:** Breaks after an hour.
- **Trigger Warnings:** These will be conveyed prior to the meeting for sensitive subjects.
- **Responsiveness**: To comments and feedback shared from participants.
- **Closing the Feedback Loop**: Ensuring feedback is addressed and communicated back to participants.
- **Showing Impact:** Demonstrating how the feedback has influenced outcomes.
- **Respect:** Consideration of everyone in the group, respecting all thoughts and opinions and allowing everyone to speak.
- **Diversity and Inclusion**: Actively engage with diverse groups in involvement activities to strive for different perspectives and experiences.
- **Accessibility:** Effort is made to ensure online meetings are accessible offering meetings in Zoom (as an alternative to Teams), with phone number options, captions, and documents in larger fonts.

8. Complaints and Grievance Procedures

We are committed to ensuring a safe, productive, and enjoyable experience for all our members. However, in the event that a patient advocate wishes to raise a complaint or grievance during the course of their involvement, the procedure and relevant contact details can be found below.

A. Public members should contact the Engagement Lead first and the Director of Corporate Services second.

The following contacts are listed below:

- Primary contact: Head of Patient and Carer Engagement Email: Kim.Rezel@hqip.org.uk
- Secondary contact: Director of Corporate Services Email: Glenn.Hearnden@hqip.org.uk
- Additional contacts for specific projects:
  - DARG public members have a named "buddy."
  - Independent Advisory Group public members have a named Associate Director and Project Manager for the project.

If further escalation is required, the issue can be taken to the CEO. Email: Chris.Gush@hqip.org.uk

B. Agreement

Each project will have a Public Involvement Agreement and/or a Terms of Reference in place, which are acknowledged or signed before the projects start. All engagement activities follow a Code of Conduct (see section 4).

C. Assessment of Complaint

1. Initial Assessment: The Engagement Lead will first check the agreements and Terms of Reference to assess whether the Code of Conduct was followed.

2. Secondary Assessment: If necessary, a mediation meeting will be organised with the Director of Corporate Services who will be mediating.

3. Timely Response: HQIP will seek to resolve the complaint promptly, ensuring all parties are heard and a suitable solution is found.

Initial assessment: The Engagement Lead will first check the agreements and Terms of Reference to assess whether the Code of Conduct was followed

Secondary assessment: If necessary, a mediation meeting will be organised with the Director of Corporate Services who will be mediating

Timely response: HQIP will seek to resolve the complaint promptly, ensuring all parties are heard and a suitable solution is found

If you have any questions about this policy, or HQIP's patient/carer engagement work more generally, please contact Kim.Rezel@hqip.org.uk

Further information can also be found on the Involving Patients section of the HQIP website.

Policy Date: **September 2024**

Review Date: **September 2025**

Thank you to all our patient advocates who take time out of their busy lives to support the work at HQIP. The patient input is invaluable, and our work would not be credible without your involvement.

This policy has been co-produced with four SUN members and reviewed by 10 others.

There are more than 100 SUN members, and we thank each and every one of you for your involvement over the years.

9. Testimonials

WHAT DO PATIENT ADVOCATES ENJOY ABOUT ENGAGEMENT AT HQIP?

Working together

Positive

Remarkable

Being treated as an equal

Listening to each other

Feeling heard

Making a difference

Feeling like part of something

Genuinely collaborative

Sharing my experiences

Co-production

It feels inclusive and transparent

> “Individually we can only do so much, collaboratively we can make positive changes; my first coproduction with HQIP was remarkable and reflected the shared key values and integrity to amplify all voices of Patient Advocates”.
>
> MT, SUN member

> “I joined a project team at HQIP, everyone's views and ideas were equal, and everyone was respectful and listened to each other. It felt genuinely collaborative, all working together to reach the end goal.” WD, SUN member