

## Specialised Healthcare Alliance Governance

The Specialised Healthcare Alliance has been established to seek uniformly high levels of care and access to all evidence-based treatments by:

- Advocacy and campaigns on behalf of people with specialised medical conditions\*;
- Using all channels to raise the profile of specialised healthcare;
- Collecting and disseminating authoritative information about the effectiveness of arrangements for specialised commissioning;
- Working with all interested parties to address and remedy problems where they arise, including integration within health and between health and social care.

In conducting its work, the Alliance focuses exclusively on overarching policies and structures relating to specialised care and does not address individual therapeutic issues. The Alliance has no political affiliation and seeks to work across all political parties.

### Membership

Membership of the Alliance is open to patient-related groups with an interest in specialist conditions and a national remit. By joining the Alliance, members agree to support its objectives and associated activity.

### Corporate supporters

Healthcare companies may apply to become corporate supporters of the Alliance. This entitles companies to attend SHCA meetings and receive SHCA communications. The Alliance's policy positions and work programme will, however, be solely determined by members.

### Chair

Members will appoint an individual of suitable standing to chair meetings and to act as a principal spokesperson in representing the Alliance to Government and other parties.

### Meetings

Meetings of the Alliance will be held at regular intervals to discuss developments of mutual interest and the Alliance's activities, with a view to ensuring the support of all members.

### Secretariat

A secretariat will be appointed to implement the Alliance's programme of activity. The secretariat is currently provided by Incisive Health.

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\*involving services requiring planning and procurement at regional or national level

**Finance**

The costs of the Alliance will be funded by corporate supporters on a breakeven basis.

**Notice and termination**

Members may decide to leave the Alliance with one month's written notice. The Alliance will be wound up when a majority of members so decide.

**January 2004, revised October 2011, July 2014, April 2016, February 2017, January 2018, January 2021, January 2022**

## **SHCA Ways of Working**

The Specialised Healthcare Alliance (the Alliance) is a coalition of patient-related organisations and corporate supporters which campaigns on behalf of people with rare and complex conditions.

The Alliance has no political affiliation and seeks to work on a cross-party basis.

## **Membership and corporate support**

Membership of the Alliance is open to any patient-related organisation with an interest in specialised services and a national remit. All members have equal status within the Alliance.

Presently, the Alliance consists of over 120 patient-related members, the vast majority of which are patient organisations, along with a smaller number of third sector service providers. The Alliance is also open to corporate supporters with an interest in specialised services. Presently, the Alliance consists of ten corporate supporters, all of whom are pharmaceutical companies.

Applications to join or support the Alliance may be made in writing to [team@shca.info](mailto:team@shca.info) and, the above criteria being satisfied, will need approval from the Chair. Members may leave the Alliance by providing one month's written notice to the secretariat.

## **Funding**

Alliance membership is free to all patient-related organisations, with its costs being met entirely by its corporate members. Corporate supporters each make an equal contribution to the costs of the Alliance on a yearly basis. The contribution for 2022 was £14,500 + VAT per company.

There is no distinction between members of the Alliance, who are solely responsible for the Alliance's policy and programmes. Corporate supporter have the right to attend meetings of the Alliance and to receive its communications but not to determine its policy and programmes.

## **Transparency**

The Specialised Healthcare Alliance is committed to working openly and transparently. All formal communication contains a declaration of the Alliance's membership and corporate supporters.

The Alliance's finances are transparently declared on its website, along with a full list of its members and corporate supporters. The name of the organisation providing the secretariat to the Alliance is also declared on the Alliance's website.

All major communications materials will bear the Alliance's transparency boilerplate, as follows:

"The Specialised Healthcare Alliance is a coalition of XX patient-related organisations, with XX corporate supporters, which campaigns on behalf of people with rare and complex conditions."

Email correspondence will include the identity of the incumbent secretariat.

## **Policy Focus**

The Alliance campaigns on the overarching policies and structures relating to NHS specialised services.

The Alliance strictly avoids involvement in any particular therapeutic area or condition, which

remain the separate focus of its individual members. The Alliance never takes a position on individual medicines or services, though may use service-specific examples to illustrate generic issues.

The Alliance's policy priorities and positions are determined only by its members.

### **Geographies covered**

The Alliance focuses on UK health services. The majority of activity related to England, with work in the devolved administrations according to available resource.

### **Decision-making**

The Alliance's quarterly meetings are the main focus of its decision-making. These meetings play the primary role in determining the Alliance's policy positions and in agreeing its activities. All members are able to attend these meetings and to contribute to discussions.

Most matters are agreed at these meetings by consensus. However, where necessary, decisions will be taken on the basis of a majority vote. Between meetings, the Alliance's secretariat takes forward members' instructions within the policy parameters determined at meetings.

For matters arising between meetings on which the Alliance will need to take a view, all members are consulted by written procedure. Draft Alliance submissions to consultations and any communications which go beyond previously agreed policy parameters are circulated to members for comments and approval with no less than seven days' notice. In cases of doubt, the secretariat will consult the Alliance's Chair for guidance.

Where decisions have been taken between meetings, the secretariat must account to members for this activity at the next quarterly meeting.

All members have an equal weighting within the Alliance and no member has a right of veto.

### **Chair**

The Alliance is chaired by an eminent public figure with an interest in services for people with rare and complex conditions. To date, each of the Alliance's Chairs has been a member of the House of Lords. The Alliance is currently chaired by Lord Sharkey.

The Chair of the Alliance is approved by members to chair its meetings and act as a principal spokesperson in representing the Alliance to government and other relevant parties. The Chair approves all new applications for membership of the Alliance, as well as corporate supporters. Chairmanship of the Alliance is a voluntary role and has no remuneration except for legitimate expenses.

The Alliance has no political affiliation and is open to candidates for Chair from across the political parties. Where possible, the Alliance will seek to have Vice-Chairs drawn from the other main political parties to the Chair's. In the past, the Alliance has at different times been Chaired or Vice Chaired by members of all three main political parties.

When a vacancy arises, the Alliance's secretariat will approach potential candidates for the Chair or Vice Chairmanship and present these to members for approval. The Chair does not have a fixed term and may withdraw from the Alliance at any time. Members may move to terminate the Chair's period in office by writing to the secretariat, whereupon a vote of the membership will be called at a quarterly meeting.

## **Secretariat and finances**

The secretariat of the Alliance is appointed by members to take forward the Alliance's work programme. In acting for the Alliance, the secretariat must work in the sole and exclusive interests of members and ensure focus on the group as a whole by adoption of Alliance branding and email addresses.

The secretariat may carry forward work within the policy positions and parameters set by members at quarterly meetings and in writing. The secretariat may also represent members as a whole in meetings with external stakeholders, reporting back to members on such meetings as a matter of course.

Corporate supporters' contributions are paid to the secretariat on a self-financing basis within each calendar year. The secretariat will account to all members for its use of resources every autumn, writing off any expenditure in excess of corporate contributions between years. This meeting will be preceded by consultation between the secretariat and the Alliance's corporate supporters to determine the likely level of resource available for the following year.

Members may choose to change the Alliance's secretariat at any time. Members with concerns about the secretariat should raise them confidentially with the Chair in the first instance, who will then request an item for discussion at the next quarterly meeting in the absence of the serving secretariat. If members choose to change the secretariat, the incumbent consultancy will assist in an orderly transition over a notice period of not less than three months.

The appointment of the secretariat will form an item on the agenda each autumn in conjunction with consideration of the following year's work programme.