

Chest Heart and Stroke Scotland  
 Regional Assemblies March 2024



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## 1. Introduction

Our Peer Participation and Engagement ambition is to implement and embed the [Engagement and Involvement Framework](#) so that everything we do to achieve our 5-year [No Life Half Lived strategy](#) is actively and meaningfully informed by people affected by our conditions. This will enhance CHSS's agility to anticipate and respond to the challenges presented by the ever-evolving health and social care landscape.

We aim for CHSS to be an exemplar of meaningful participation and engagement – actively leading the way; trying and creating new ways of doing things; bringing our partners and stakeholders with us on the journey to a fully co-produced services offer.



The existing Peer Support Group network is as an integral part of the Engagement and Involvement Framework, recognising the invaluable role the members play in our collective mission. The Framework enables the effective flow of information, and meaningful communication and collaboration that redresses power imbalances via locally based Peer Group Clusters, Regional Assemblies, and the National Advisory Panel. ([Appendix 1: Engagement Structures](#))

Our first round of **Regional Assemblies** which were held throughout March in Edinburgh, Dumfries, Inverness, and Glasgow were an enormous success. Feedback is extremely positive indicating a clear appetite for continued engagement and endorsing our plans for the Participation and Engagement Framework.

The [Event Evaluation](#) is attached at [Appendix 2](#).

## 2. Purpose and Objectives

The main purpose of the first round of Regional Assemblies was to share information with Peer Support Group members and obtain their feedback and ideas:

- To inform implementation of the NLHL strategy and service delivery,
- To inform the ongoing review and development of the peer support network, and
- To shape future Regional Assemblies.

### The objectives were:

1. To update Peer Group members on the results of the One in Five Survey and obtain feedback and ideas to inform future campaigns and service developments.
2. To provide information about the new No Life Half Lived Strategy including the Community Healthcare Support Services Offer and obtain feedback and ideas to inform implementation of the strategy and service delivery.
3. To update Peer Group members on the recommendations of the Rocket Science Review and obtain feedback on our proposals to support the expansion of the Peer Support Network and develop the CHSS relationship with Peer Support Groups and obtain feedback and ideas to inform further developments.
4. To Provide networking opportunities across different Peer Groups; share experiences, challenges and contacts; explore solutions and pool resources.
5. To hear from participants about their ideas and preferences for the format and content of future Regional Assemblies to inform the design and delivery of future events.



### 3. Participants

Invitations were sent to the named contacts for the Peer Support Groups in the operational geographic area for each of our Peer and Involvement Coordinators, roughly:

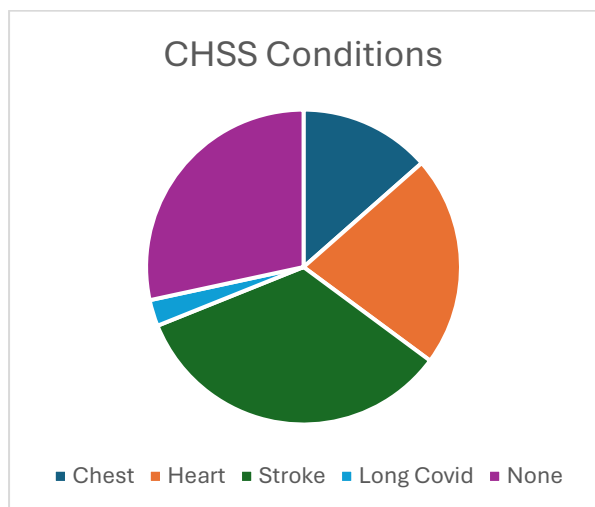
- For the Edinburgh Event invitations were sent to Peer Support Groups in the East of Scotland: Georgia Freyne’s operational Area.
- For the Dumfries Event, invitations were sent to Peer Support Groups in the South of Scotland: Christine Wakefield’s operational area.
- For the Inverness Event, invitations were sent to Peer Support Groups in the North of Scotland: Laura Campbell’s operational area.
- For the Glasgow Event, invitations were sent to Peer Support Groups in the West of Scotland: Tim Clark’s operational area.



The events were open to any Peer Support Group member with priority being given to named contacts and committee members/organisers. Due to venue capacity, there was a cap of approximately 20 people at each event.

The 4 events were attended by 72 people from 26 different Peer Groups.

- 27 people attended in their capacity as a Peer Group committee member/organiser.
- All our conditions were represented in the following proportions: Stroke 47%, Cardiac 30%, Respiratory 19%, and Long Covid 4%.



#### 4. Event Overview & Key Highlights



Here is a copy of the [programme](#) which was broadly the same for each event. Following feedback from the Edinburgh event we added time at the start of the subsequent events for all the participants to introduce themselves and indicate which Group they were from.

Office and Facilities provided goodie bags for each participant including CHSS merchandise, a copy of the NLHL strategy, CHSS notebook and pen. Advice Line cards/mini booklets and laminated “you said/we did cards” were available on each table. CHSS pop up banners were displayed at each event.

Each session was followed by an opportunity for discussion. The session topics were:

1. *One in Five Survey results*
  - Future Campaigns/Research
2. *No Life Half Lived Strategy*
  - Focussing on the Community Healthcare Support Services Offer
3. *Peer Developments*
  - Rocket Science Review (a summary of the report was circulated to participants in advance and hard copies distributed around the tables on the day).
  - Activity to implement recommendations: You said, we did
  - Development of the CHSS relationship with Peer Support Groups
4. *Participation and Involvement Framework*
5. *Format and Content of Future Regional Assemblies*

Here is a copy of the [Master slide Show](#).

Here is a [Summary of the Rocket Science Report](#).

Here is a copy of the [You Said, We Did Cards](#).



### Social Media

We obtained everyone's permission to take photos and the events were promoted on Facebook and X (formerly Twitter).





## 5. Discussion Sessions

There were staff members at each table during breakout discussions, prompting the conversation and taking notes.

The discussion notes have been typed up and organised into themes. The collated notes have been uploaded onto our Teams Site and the feedback and ideas will inform strategy implementation, service delivery, campaigns, and Peer developments.

Here is a copy of the [spreadsheet of the discussion notes organised by theme](#).





## Comments and Suggestions arising from Discussion Sessions

### *Purpose/Running of Peer Groups*

- Peer groups serve as social hubs for mutual support and activities.
- Committee members/Group organisers just want to get on with attending and/or running their group. Don't want to get bogged down with bureaucracy, paperwork, and forms.
- Groups are looking for a model that's based on relationships, information sharing and arm's length support rather than close affiliation.
- Groups are looking to CHSS to provide advice, guidance, and templates and contacts for guest speakers.
- Proposal for regular Q&A sessions with CHSS representatives – online drop-in sessions or newsletter style Q&A update.
- CHSS to provide advice on PVG checking, health, safety requirements, and financial support.
- CHSS to offer guidance on fundraising, applying for funding, and succession planning.

### *Expansion of the Peer Support Network*

- The strategic ambition to expand the Peer Network from 3k to 10k members over the next 5 years was welcomed as this enables more people to benefit from the positive impact of peer support/lived experience support.
- Recognised that volunteers and online provision are integral to our Peer expansion plans.

### *Volunteer/CHSS Staff Support*

- A formal CHSS Volunteer role was proposed, allocated to a geographic cluster of Peer Groups. They can provide practical support to their local Peer Groups and act as a contact point between you and CHSS. They will work directly with the Peer Groups in their cluster and liaise between the Groups and coordinators.
- There was general support the concept of geographical clusters of Peer Groups with dedicated CHSS "Peer Connector" volunteers for support and liaison.
- Local connector volunteers can provide in-person contact with Peer Groups, provide information about CHSS services and signpost to local activities and information.

### *Digital/Online Presence*

- There was an acknowledgment of the importance of online provision as an alternative or supplementary to in-person groups
- There is a common misconception that older people are reluctant to embrace digital technology and online platforms. Many older people are digitally literate and keen to use digital technology to access tools and make connections – especially those in remote and rural areas where there is often no alternative.
- There isn't one size fits all – some people prefer face to face engagement and others are comfortable with online provision.
- Online provision means that Peer Support Groups can be available to people who live in remote and rural areas and where there are transport or mobility/health barriers prevent people being able to attend in person.





- Groups would like access to an online/digital platform where templates, guidance and resources can be shared and downloaded without having to go to CHSS coordinators to request information.
- It was suggested that CHSS could develop an app for the provision of templates, information and advice, or as a way for Peer Groups to share information and keep in touch.

#### *Paperwork/Regulatory Support*

- Groups want to be responsible for their own regulatory processes such as health and safety, risk assessments and PVG, but they indicated that they need CHSS advice and guidance.
- They want to hold and control their own documentation but there are situations where they would like CHSS to act as a broker and/or umbrella organisation – for example, PVG and insurance.
- Groups don't want CHSS monitoring or imposing restrictions over group activities.
- Groups would like access to an online/digital platform where templates, guidance and resources can be shared and downloaded without having to go to CHSS coordinators to request information.

#### *Insurance*

- Not all groups need CHSS insurance cover. Some are charities in their own right and others are covered by another organisation's insurance.
- General consensus is that an opt in system would be appropriate for CHSS insurance, depending on each group's specific needs and activities.

#### *Funding*

- There was general support for the concept of a small annual endowment for Peer Groups – to assist with day to day running costs such as venue hire, flyers/promotional materials, transport.
- Some Groups have more funding than others. Some have access to grant funding and undertake their own fund-raising activities.
- Groups would like CHSS to ring fence a pot of money which individual groups can apply to for specified purposes. This would assist with match funding for grant applications, one off trips/activities, sporting or other equipment etc
- Groups would like to explore making joint fund-raising and joint grant applications with other Groups.

#### *Physical Activity/Exercise*

- There was universal recognition of the benefits of physical activities for mental and physical health, emphasizing the need for structured activities and trained instructors.
- There were requests for access to sporting equipment like boccia sets and suggestions for partnerships with Local Authorities for storage and access to facilities.

#### *Transport*

- Lack of transport was highlighted as a significant barrier. Groups are keen to explore community transport options
- Groups can share information about transport provision in their area – facilitated by CHSS Peer Connector volunteers.

### *Lived Experience Connections*

- The value of making connections with people with lived experience at as early a stage as possible in the recovery journey was highlighted at every event.
- Hearing from someone who has experience of the person's condition can provide reassurance, practical information, advice, and hope at a stage when they are feeling scared and unsure of what to expect.
- It was suggested that peer support should be offered in hospital and immediately on discharge.

### *Networking and Collaboration*

- There is a need for increased communication and collaboration among Peer Groups to share best practice, joint fundraising and joint grant applications, pooled resources including transport and equipment.
- It was suggested that CHSS can facilitate local Groups getting together by making the connections and sharing information.
- Participants are interested in exploring partnerships with other 3<sup>rd</sup> sector organizations like Citizens Advice Bureau, Disability Scotland, RNIB, Visibility Scotland for additional support and activities.
- They would like to pursue partnerships with Local Authority or private leisure centres for access to facilities and equipment.

### *NHS/Referral Pathways*

- There were repeated calls for improved referral pathways from NHS to Peer Groups, including automatic referrals (from primary and secondary care – Hospitals and GP practices) and better integration into healthcare processes.
- Information about Peer Groups should be more widely available, including leaflets, posters, and social media support, to ensure wider community awareness and accessibility.

### *Campaigns/Policy*

- Peer Groups want to be involved in CHSS campaigns addressing issues like access to thrombectomy and rehabilitation services, with a focus on raising awareness and advocating for improved services.



### *Format and Content of Future Assemblies*

- There was a general consensus in favour of regular but focused events with input from partner organisations, Local Authorities, and healthcare professionals, dovetailing with the National Advisory Panel (NAP).
- The Groups requested shorter, single-issue events covering topics of local importance with invited speakers from the NHS, private, public and 3<sup>rd</sup> sector partners.
- It was proposed to continue with the in-person Regional Assemblies on a rolling basis with one event at a time, every 1 or 2 months, moving around the Country in a different region each time so that there are at least two every year in each region. It was proposed to hold regular online events for those who are not able to attend in person.
- Provide opportunities for networking, informal discussions, and interactive workshops.
- Facilitate discussions on local issues and provide information about what's available in their area/community.
- Incorporate exercise ideas, physical activity, arts, and crafts.



## 9. Recommendations

1. It is recommended that **CHSS maintains an arm's length relationship with Peer Support Groups** facilitating connections between groups and with NHS and Local Authority partners; providing advice, guidance and templates and acting as an umbrella organisation for regulatory requirements like PVG and insurance on an opt in basis.
2. To enable a significant expansion of the Peer Support network over the next 5 years, it is recommended that CHSS will:
  - a. **Introduce a new Peer Connector Volunteer role** to act as the Groups' point of contact with CHSS. This will be a locally based formal CHSS volunteer with responsibility for a cluster of Peer Support Groups in their geographical area.
    - This will facilitate better connections between local Peer Support Groups to share information, resources, and equipment.
  - b. **Create an online Peer Support Network**, including:
    - Providing digital support to Peer Support Groups, including advice, guidance, tools, and hardware.
    - Exploring the creation of or adopting an existing app and/or online portal for resources, templates, and guidance and for making connections.
3. It is recommended exploring the provision of a **small annual endowment** to Peer Support Groups and/or creating a **Peer Support fund** or pot of money which Peer Support Groups can apply to on a one off or recurring basis.
4. It is recommended that CHSS **raises awareness of Peer Support Groups** to NHS, Local Authority, and 3<sup>rd</sup> Sector Partners; explores an **automatic referral** to Peer Support shortly after the event or diagnosis; **facilitates early Peer Support intervention** so that people can connect with someone who has **lived experience** of their condition at the earliest opportunity.
5. It is recommended the CHSS organises a **rolling programme of in-person Regional Assemblies** with one event at a time, every 1 or 2 months, moving around the Country in a different region each time so that there are at least two every year in each Region.
  - a. These will be shorter, single-issue events covering topics of local importance with invited speakers from the NHS, private, public and 3<sup>rd</sup> sector partners.
  - b. The in-person events will be supplemented by regular online Assemblies for those who are not able to attend in person.



### **PARTICIPATION & ENGAGEMENT FRAMEWORK 23/28**

"CHSS is **wholly committed** to the principles of **engagement**"

We are committed to the **active & meaningful involvement** of people affected by our conditions in the development, delivery & evaluation of our services

Central to ensuring no life is half lived as a consequence of our conditions is their **active and systematic involvement** in making this a reality



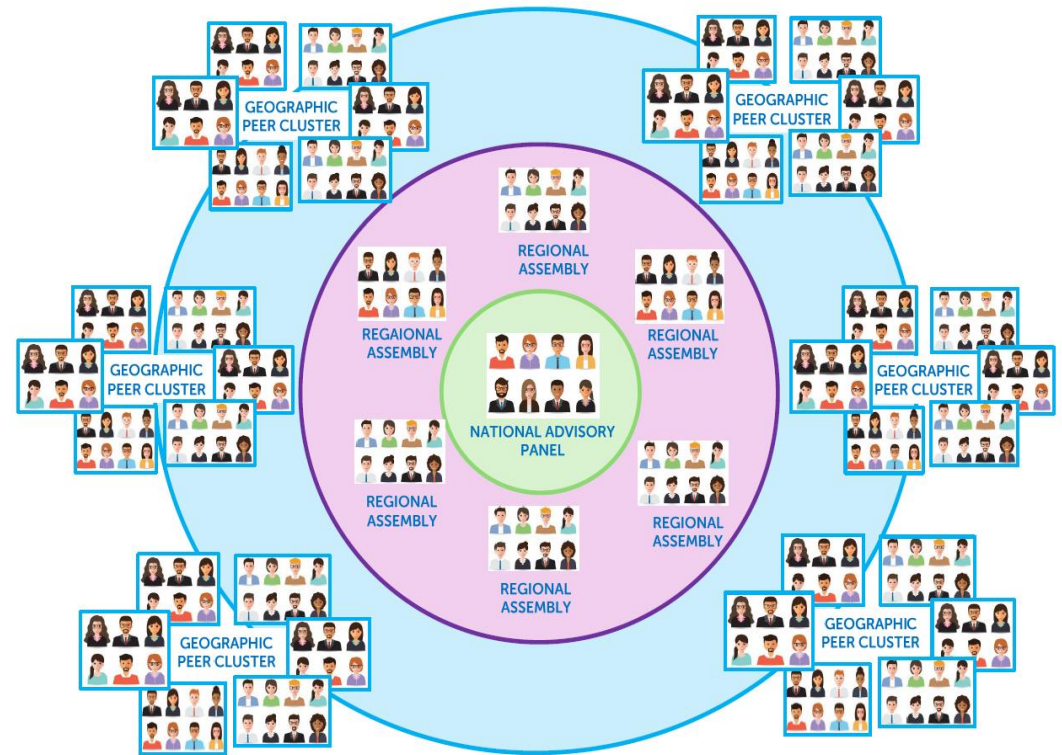
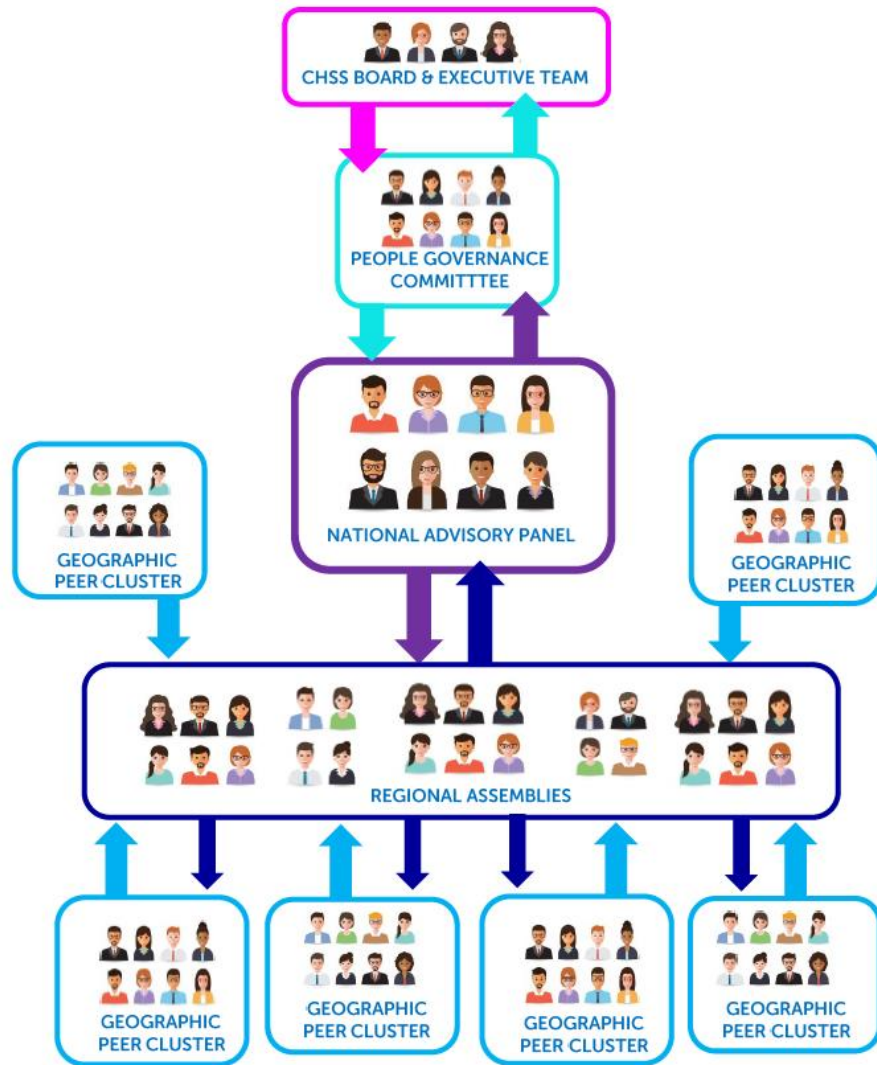
## **Thank you.**

Enormous thanks to everyone who helped organise our March 24 Regional Assemblies.

Thank you to the Peer Group members, guests, and people affected by our conditions for taking part and offering your feedback and comments.

We had a blast, and we look forward to seeing you at future events.

**APPENDIX 1: Engagement Structures**



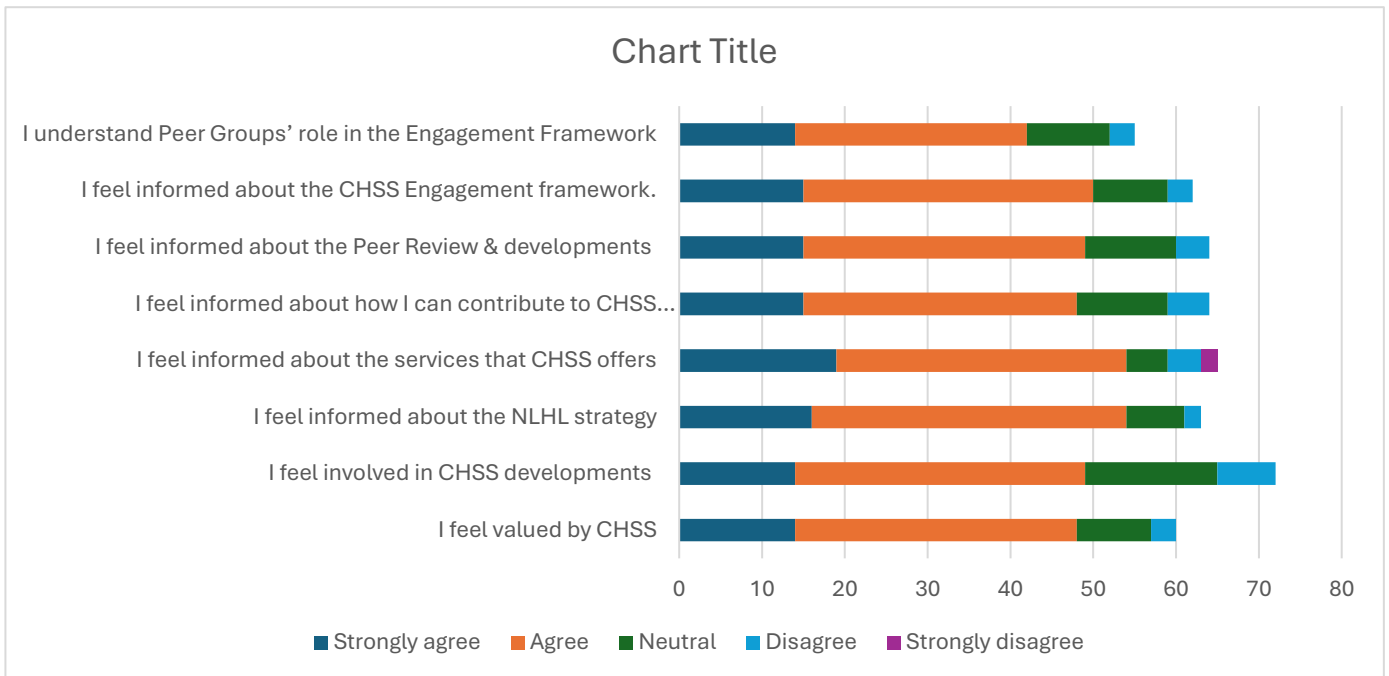
**NO LIFE HALF LIVED**

**APPENDIX 2: Event Evaluation**

All 72 participants completed an evaluation form on the day of their event. Here is a copy of the [overall evaluation report](#).

**CHSS Engagement**

- The majority of participants felt valued by CHSS (81% agreed or strongly agreed).
- A large proportion felt involved in CHSS developments (79% agreed or strongly agreed).
- Most participants felt adequately informed about the NLHL Strategy, CHSS services, and how they can contribute to CHSS developments (ranging from 73% to 88% agreement).
- Understanding of the Peer Groups' role in the Participation and Engagement Framework was slightly lower (77% agreement).

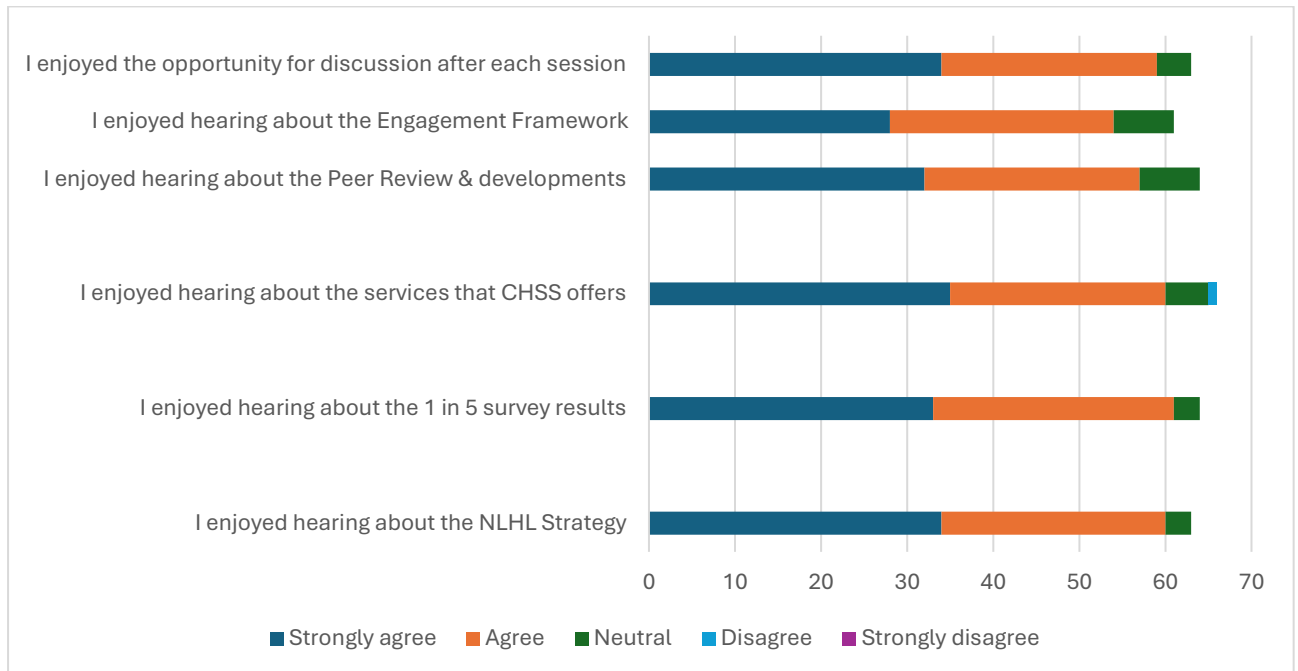


**General Feedback**

- Participants appreciated the opportunity to meet other groups, share experiences, and learn from each other.
- Some logistical issues were noted, such as difficulties with hearing, accessibility issues, temperature and venue conditions, and technical issues with sound.

*Enjoyment of the Event*

- Participants generally enjoyed hearing about the NLHL Strategy, 1 in 5 survey results, CHSS services, Rocket Science Review, and Participation and Engagement Framework (ranging from 87% to 97% agreement).
- The opportunity for discussion during and after each session was appreciated by the majority (94% agreement).



*Overall Satisfaction*

- The majority of participants found the event worthwhile and enjoyable (ranging from 86% to 92% agreement).
- Most participants found the timings and presentations suitable (ranging from 93% to 96% agreement).

