

Cross-Party Group on Visual Impairment

Wednesday 1 February 2023, 13.00-14.15 via Teams

Minute

Present

MSPs

1. Stuart McMillan MSP
2. Colin Smyth MSP

Invited guests

1. Susan Shippey, Senior Sensory Loss Policy Manager|Support for Sensory Loss and Augmentative and Alternative Communication Team, Scottish Government
2. Professor Margaret (Mags) Watson, GTAP Professor of Health Services Research and Pharmacy Practice, University of Strathclyde

Observers

1. Karen Mowat, Scottish Government
2. Mike Stewart, Scottish Government
3. Lesley-Anne Watt, Scottish Government

Non-MSP Group Members

1. James Adams, Director, RNIB Scotland
2. Paul Bartley, Optelec
3. Claire Black, NHS Education for Scotland
4. Ian Brown, RNIB Scotland
5. Catriona Burness, RNIB Scotland
6. Lesley Carcary, seescape
7. Bruce Christie, RNIB Scotland Advisory Committee
8. Eileen Clarkson, RNIB Scotland
9. Elizabeth Docherty, Optometry Scotland
10. Niall Foley, Guide Dogs Scotland
11. Claire Forde, RNIB Scotland Advisory Committee
12. Laura Gray, Macular Society
13. Sheila Hands, NHS Tayside
14. Gillian Hallard, RNIB Scotland
15. Kirstie Henderson, RNIB Scotland

16. Colin Hilditch, Sight Scotland and Sight Scotland Veterans
17. Thelma Ingram
18. Lisa Kelly, Scottish Association of Visual Impairment Educators (SAVIE)
19. Elizabeth McCann, Scottish Sensory Centre, University of Edinburgh
20. Fiona McDonald, Sight Scotland and Sight Scotland Veterans
21. Iona McLean, Macular Society
22. Maureen MacMillan, Sight Action
23. Jo MacQueen, RNIB Scotland
24. Hazel McFarlane, Scottish Sensory Hub
25. Carla Marchbank, NESS
26. Gillian Mitchell, Sight Action
27. Michael Moore, Guide Dogs Scotland
28. Sally Paterson, Vision Support Service, Aberdeen City Council
29. Mary Rasmussen
30. Professor John Ravenscroft, Scottish Sensory Centre, University of Edinburgh
31. Ken Reid
32. Terry Robinson
33. Allan Russell, RNIB Connect Radio
34. Kirin Saeed
35. Craig Spalding, Sight Scotland and Sight Scotland Veterans
36. Alan Stewart
37. Danny Sweeney, North Ayrshire Council
38. Mhairi Thurston, VI Charity Sector Partnership Mental Health Committee
39. Cirta Tooth, NHS Lothian
40. Colette Walker
41. Sandra Wilson
42. Jacquie Winning, Forth Valley Sensory Centre

Apologies

1. Jeremy Balfour MSP
2. Miles Briggs MSP
3. Scott Cassidy, Blind Veterans
4. Jacqueline Cowan, Police Scotland
5. John Donaldson, Sight Scotland - Scottish Braille Press
6. Mairi Graham
7. Gillian Heavie, Scottish Government

8. Margaret Jackson, RNIB Scotland
9. Joan Kerr
10. Sheila Mackenzie, Scottish Sensory Centre, University of Edinburgh
11. Gwenn McCreath, Vision PK
12. Terry Moody
13. Rod Murchison
14. Paul O’Kane MSP
15. Hussein Patwa
16. Janet Pooley, Scottish Government
17. Nicoletta Primo, Sight Scotland and Sight Scotland Veterans
18. Susan Robinson

Agenda item 1 - Welcome, introductions and apologies

Stuart McMillan MSP welcomed everyone to the meeting. Introductions and apologies were acknowledged, and the General Data Protection Regulation (GDPR) statement was read. Individuals attending who do not want to be named in minutes should let the Secretary know.

Agenda item 2 - Approval of minutes of meeting of 5 October 2022

The minutes were proposed by Gillian Mitchell, seconded by Terry Robinson, and then approved.

Agenda item 3 - Matters arising and Action Points report

The Action Points from the last meeting were read out:

3.1. – 3.4. Employment

3.1. The Secretary passed on Mhairi Thurston’s details to the DWP speakers so she can feed in views on how to make the Access to Work claims process more accessible to people with visual impairment.

3.2. The Secretary forwarded the DWP presentation and contacts to the CPGVI mailing list. DWP advised using their team inbox at Disabilityservices.advocacyteam@DWP.gov.uk. This will ensure that emails are picked up if an individual is out of the office.

3.3. Maureen Mcallister referred to the Access to Work Forum in Scotland and England.

3.4. Laura Walker will contact Sarah Marshall of DWP to discuss support available to enable visually impaired people to recruit support workers.

3.5. NEC Cards and +1 Cards

The Secretary collaborated with Sight Scotland on drafting a letter to the Scottish Government on behalf of the CPGVI, asking what they can do to increase the uptake of registered people applying and getting NEC cards and to highlight the campaign run by Sight Scotland to provide free +1 companion travel.

3.6. Cost of living crisis

The CPGVI Convener was to write to the Deputy First Minister/acting Finance Secretary asking what can be done at the Scottish level, including raising the possibility of seeking to apply the pension triple lock to benefits. Post-meeting, this action was overtaken by the DFM/Finance Secretary announcing in December 2022 that Scottish Government benefits will be uprated by over 10 per cent.

Agenda item 4 - See Hear Strategy 2024: Progress and Future Plans

Speaker: Susan Shippey, Senior Sensory Loss Policy Manager, Augmentative and Alternative Communication Team (AACSL), Scottish Government (SG) - susan.shippey@gov.scot.

Susan Shippey led on sensory loss services and was the See Hear strategic lead for the City of Edinburgh Council. She is on secondment to the Scottish Government Alternative Communication Team and Sensory Loss policy team until March 2024. Her key role is to refresh the Scottish Government/COSLA See Hear Strategy, originally published in 2014.

The Secretary will circulate a full note of Susan's presentation with the minutes. Key points are below:

- The See Hear strategy is the 2014 Scottish Government/COSLA strategy for people with sensory loss. The strategy is implemented through a network of See Hear leads in each Health and Social Care Partnership area with an annual allocation of £320,000 annual allocation split on a population basis.
- As its 10-year anniversary approaches, the strategy is due a refresh and engagement work with stakeholders is now being conducted. This includes:
 - A series of “deep dive conversations” with See Hear Leads.
 - Involving people with lived and living experience through a new network being set up by the Scottish Sensory Hub.

- Third sector sensory loss organisations involvement including a Scottish Government Sensory Loss in Social Care Advisory group, with its first meeting in March 2023.
- Establishing a cross-policy network of over 80 colleagues who have an interest in sensory loss and work across Scottish Government departments.
- Holding a workshop on the See Hear strategy at the upcoming Scottish Vision Strategy (SVS) conference on 8 March 2023.
- Opportunities for engaging with the deaf and deaf blindness sectors are also being considered.
- Key findings so far from the engagement work undertaken with See Hear Leads are listed in Susan’s full presentation circulated with the minutes.
- Key policy developments since 2014 also need to be included in the renewed strategy.

In summary, there is a commitment to refreshing the strategy and aiming for more congruence between high level aims and recommendations or actions, including involving people with lived and living experience throughout. Please contact susan.shippey@gov.scot if you would like to be involved or to have more information on any of the above points.

Questions and answers

Question (Q)1: Appropriate use of language was raised. This included using “sight loss” as a description for visual impairment, particularly amongst people who are born with no or little sight.

Answer/response (A)1: Very much acknowledge the importance of using language particularly when it is used in framing discussions. It is hoped the new See Hear Strategy will include descriptions and reference points on terminology used within it. “Sight loss” has been used as a short-hand way of describing visual impairment but it must be acknowledged this description does not cover everyone’s experience.

Q2: The importance of children and young people’s experience being integrated within the renewed strategy was emphasised and the Scottish Sensory Centre is keen to work with See Hear colleagues on this.

A2: In agreement that children and young people must be integrated throughout the new strategy. Work is underway within Scottish Government to ensure policy areas such as support and wellbeing, and

education are prioritised throughout its development and welcome further collaboration with the Scottish Sensory Centre to strengthen this.

Q3: When the strategy was first launched in 2014, some of the diagrams it contained, for example charts, were not fully accessible for those using screen reading software.

A3: There is a clear commitment to producing accessible information throughout the renewed strategy including using appropriate alternative text and descriptions when using images, diagrams, and charts. Feedback from CPGVI members on accessibility is most welcome.

Q4: The Covid pandemic saw some people with visual impairments having poor access, both in terms of physical access to appointments at clinics, and the inaccessibility of communications and Covid testing kits sent out. It is vital to keep inclusive engagement at the core of the strategy and address ongoing barriers in health and social care settings.

A4: The Scottish Sensory Hub can advise on accessible information and is working closely with Scottish Government and other partners to ensure it is embedded within health and social care.

Q5: Is it useful to combine both hearing and visual impairment under the umbrella strategy of “See Hear”?

A5: Acknowledge both visual and hearing sensory impairment, can impact very differently on an individual’s experience of the world around them. Within health and social care, commissioning of services has included both those which cater for people with hearing and/or visual impairment, as well as dual sensory loss. Trends suggest that with an increasing ageing population there are more people experiencing dual sensory loss, so the rationale is to commission and develop strategy under the combined banner of hearing and vision. It may be relevant to include specific recommendations in the new strategy for those who have visual or hearing impairment, whilst recognising those with dual sensory loss.

Q6: This underlined the earlier point raised about using appropriate language to describe vision impairments. The concept of “loss” may not apply to people born with a visual impairment.

A6: Acknowledged the importance of the use of language and diverse experiences of the VI population, which is why inclusion of those with lived experience is so vital to strategy's development.

Convener Stuart McMillan thanked the speaker and reiterated her request that those present at the CPGVI engage with their membership and contact Susan directly about this work.

Action Point 4.1:

If you, as an individual with lived and living experience, or as an organisation wishing to join the See Hear Strategy advisory group, and/or respond to any other aspect of this work please let Susan Shippey know by emailing susan.shippey@gov.scot.

Agenda item 5 - Older people with visual impairment and the safe and effective use of medicines

Speaker: Margaret (Mags) Watson, GTAP Professor of Health Services Research and Pharmacy Practice, University of Strathclyde - margaret.watson@strath.ac.uk.

Mags Watson is Professor of Health Services Research (HSR) and Pharmacy Practice in the Strathclyde Institute of Pharmacy and Biomedical Sciences, University of Strathclyde. She is a Fellow of the Royal Pharmaceutical Society and has her own consultancy business. Her research aims to develop evidence-based solutions to support the safe and effective use of medicines by older people with sensory impairment (visual and/or hearing)

The Secretary will send a full transcript of the presentation along with minutes of the meeting. This is an abridged version for the minutes.

Mags leads on a research programme called the SIPA2 Study which is exploring the medicine-related needs of older people, i.e., individuals aged 65 years and over, who have sensory impairment – visual, hearing or both. Her presentation to the CPGVI focused primarily to older people with visual impairment. The definition of visual impairment includes all degrees of impairment or loss whether it is congenital or acquired.

Key points included:

- As we age, we develop more health conditions, many of which are treated with medicines. The more medicines we use the greater the likelihood of medicine-related problems occurring.
- Older age is also associated with an increased risk of visual impairment; sight loss is likely to increase in Scotland in coming years with an ageing population.
- This combination of factors is a perfect storm in terms of the safe and effective use of medicines. Incorrect use of medicines can result in deteriorations in health, reduced quality of life and increased need for additional healthcare as well as harm arising from incorrect doses and missed doses.
- One in six outpatient appointments in Scottish hospitals are for eyecare and estimates suggest that the NHS and public sector spend £194 million annually on eye disease with additional costs to the economy and society estimated at around £434 million.
- The study is funded by the Dunhill Medical Trust with research contributors based in universities across the UK but mainly in Scotland.
- The research team are collaborating closely with people with sensory impairment, third sector organisations, policy representatives and others. They have reviewed existing evidence to learn about the challenges faced and solutions that older people with visual impairment adapt for managing their medicines.
- More can be done to support healthcare professionals in helping older people with VI manage their medicine needs. A free online educational resource called a Massive Open Online Course (MOOC) has been devised and will launch on 13 February 2023. The course was designed primarily for health and social care professionals, but everyday language is used throughout, and members of the public could also complete it if they wish. The course was designed to be undertaken over four weeks, but people can complete it at their own pace.
- Following engagement with multiple stakeholders, many of whom are older people with VI and VI third sector agencies, it is hoped there will be opportunities to co-producing recommendations from the study. This may help shape what the future of medicine-related services and products should look and feel like, to better support the safe and effective use of medicines by people with VI.

Further work as part of this study includes development of a website which people will be able to search to identify products and devices that

may help older people with VI manage their medicines; and funding has been secured to support four PhD students to do further research.

Mags then outlined opportunities for CPGVI members to get involved such as sharing your experience and expertise; attending events; and sharing information about the MOOC so that as many people as possible can undertake it and become, better informed about the medicine-related needs of older people with sensory impairment.

Stuart thanked Mags and opened the meeting up to questions:

Questions and answers:

Q1: Mags was asked whether the Dunhill Medical Trust has any association with the tobacco industry. And will the research extend to include all those aged 65 and above with some form of sight loss - not just those who are registered as severely sight impaired (SSI) or sight impaired (SI)?

A1: The Dunhill Medical Trust has no association with the tobacco industry. This link gives information on the Dunhill Medical Trust [Home - The Dunhill Medical Trust](#).

The research includes people registered as SI or SSI, as well as those who are not. The funding criteria of the research means only those aged 65 years old and above can participate but the findings and recommendations could potentially benefit the whole VI community.

Q2: Often the format of standard print prescriptions is inaccessible with small font size. At present, it is unclear whether large print prescription formats are available on request. Some people must forgo their privacy when they are unable to read the current standard format of a prescription by requesting others read it out for them. It would be helpful if there was one standardised way of highlighting clearly on a person's health record that they require an accessible format.

A2: Thanked for raising this point. Hope this is an area one of the PhD researchers can explore. Further research is required, including identifying the key players on any changes to the centralised national system, and looking at the systems community pharmacies use when issuing prescriptions.

Q3: Will the research look at the design and layout of pharmacies and other healthcare settings (e.g., GP surgeries and pharmacies)? Sometimes the design and layout of the physical environment presents a barrier for people with VI. For example, pharmacy counters are often situated at the back of a shop, making them difficult to locate and navigate to if using a navigation cane or guide dog, particularly if there are narrow walkways to get there.

A3: Mags agreed that participants in research should be kept informed of the eventual findings and recommendations.

Stuart thanked Mags for her presentation and the contributions from the audience. She also urged members to get in touch directly with her with further questions or points to discuss.

Action Point 5.1:

The Secretary will send the full presentation transcript and contact details - margaret.watson@strath.ac.uk - to the CPGVI mailing list. The MOOC course link will also be sent to the CPGVI members, and the Convener will send the course link to all MSPs.

Agenda item 6 - Any other competent business

James Adams, Director, RNIB Scotland reported that invitations have been circulated for the upcoming Scottish Vision Strategy (SVS) conference in Edinburgh at Dynamic Earth on 8 March 2023. He urged all those present to sign up/register for a place, and to circulate the invitation amongst wider networks.

Action Point 6.1:

The Secretary to send conference registration details to the CPGVI mailing list.

Agenda item 7 - Date of next meeting

To be confirmed.

Feedback was sought on the best format for future meetings. The meeting agreed that a hybrid meeting format may be most suitable and that the option to join online should remain available.

Stuart McMillan thanked all those in attendance at the meeting including speakers and closed the meeting.