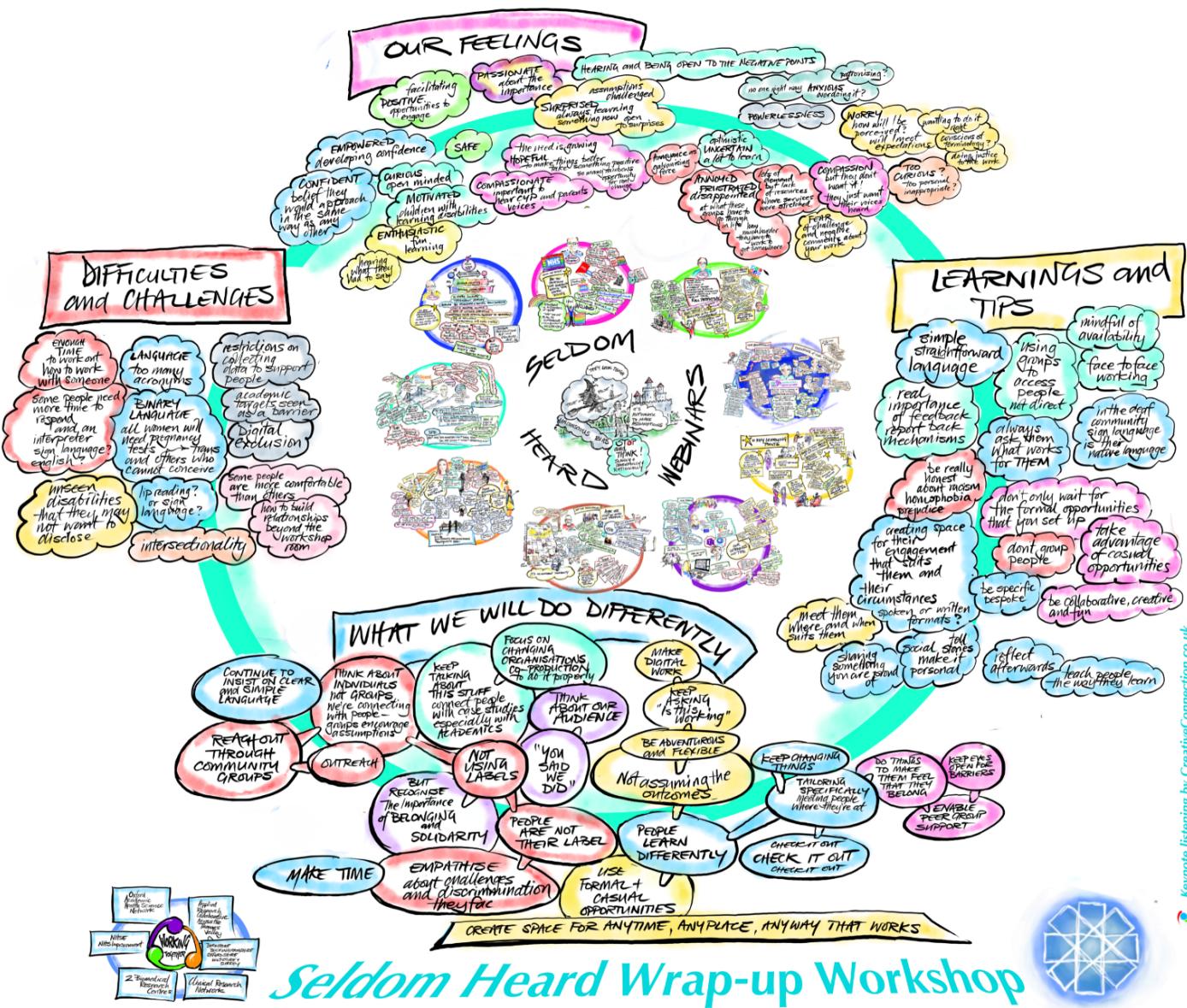


Seldom Heard wrap-up workshop report

Report prepared by Lucy Walters, Oxford AHSN



Contents

Background	2
Key themes and outcomes from the breakout sessions	3
Session 1 – emotion card exercise on people’s experience of working with seldom heard groups.....	3
Session 2 – experiences of working with Seldom Heard groups	6
Session 3 – what next?	8
Appendix1.....	9
Appendix2.....	35

Background

This workshop was the final event in the series of workshops on ‘Inclusion for all? Working with the Seldom Heard’. The other three webinars in the series were:

LGBTQ+ Community, 2 November 2020

Learning Disabilities, 19 November 2020

Sensory Impairments, 7 December 2020

The recordings of all three webinars from last year can be viewed [online here](#), and a combined PDF report from each event can be found in appendix 1.

These events were organised by the [Working Together Thames Valley Partnership](#), which consists of the following organisations:

[Oxford Academic Health Science Network \(AHSN\)](#)

[NHS England South East](#)

[NIHR Oxford Biomedical Research Centre \(BRC\)](#)

[NIHR Oxford and Thames Valley Applied Research Collaboration \(OTV ARC\)](#)

[NIHR Oxford Health Biomedical Research Centre \(BRC\)](#)

[NIHR Clinical Research Network Thames Valley and South Midlands](#)

[NIHR Research Design Service, South Central \(RDS\)](#)

Hosts

Siân Rees – Oxford AHSN

Douglas Findlay – Oxford AHSN

Lucy Walters – Oxford AHSN

Polly Kerr – NIHR Oxford Biomedical Research Centre (BRC)

Claire Schwartz – NIHR Oxford and Thames Valley Applied Research Collaboration (OTV ARC)

Claire Murray – NIHR Oxford Health Biomedical Research Centre (BRC)

Oliver Evans – NIHR Clinical Research Network Thames Valley and South Midlands

Cora Reilly-McGeown – NIHR Clinical Research Network Thames Valley and South Midlands

Illustrations

The visual illustrations in this report have been produced by [Creative Connection](#)

Key themes and outcomes from the breakout sessions

Session 1 – emotion card exercise on people's experience of working with seldom heard groups

This session was formed in part from the pre-work questions sent in advance of the workshop, which asked attendees to look through 24 emotion cards (12 positive and 12 negative) – see the 24 cards within the briefing paper in appendix 2. We asked them to consider the question: *When thinking about working with Seldom Heard groups, what emotions come to mind?* Attendees were asked to select one positive and one negative card that best described how they feel in response to this question.

Attendees were split into four groups (mix of clinicians and members of public), and the facilitator of each group shared their screen with a PDF of the 24 emotion cards and kept a tally of their group's responses. Each breakout group then fed back to the whole group, and we made a collective tally of cards chosen – see figures one and two below.

There was an obvious trend with the positive emotion cards that were chosen by attendees, with many duplications and several cards not being selected at all.

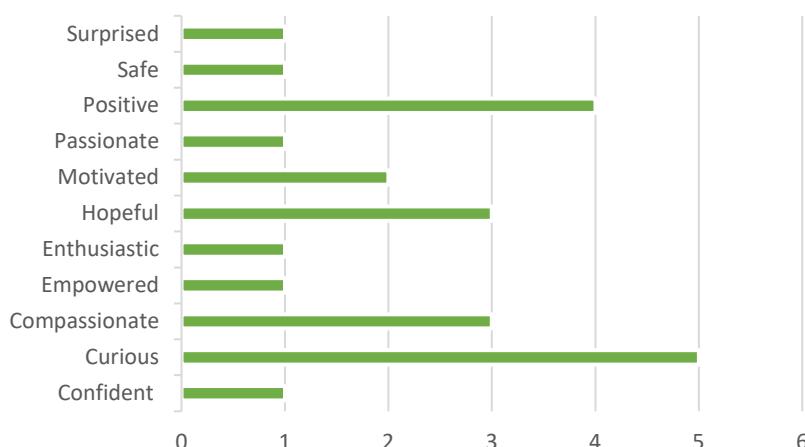
The most popular positive emotion expressed was *curious*. Attendees described feeling this emotion when considering what the outcomes of their work will be, and a deep curiosity to learn and educate themselves more in this area of work, whilst also anticipating but being open to surprises. One group had a detailed discussion as to whether 'curious' was a truly positive emotion or if it also had negative connotations – could you be too curious and start to ask questions that would be considered inappropriate and too personal?

Curiosity was closely linked with feeling *enthusiastic* and *positive* with many using them in conjunction with each other when describing how they feel when helping facilitate conversations with people who find it hard to access information and research. One facilitator described feeling particularly enthusiastic after completing a recent piece of work that was fun and which had really pushed them to want to do more similar work.

When making specific references to working with young children with disabilities and their parents, attendees described feeling extremely *motivated* and *compassionate*. The emotion *compassionate* also evoked a debate within one group. Some attendees highlighted that seldom heard groups don't want our compassion, they just want opportunities to be heard. They don't want sympathy or to be disempowered, they want to make a difference and have a voice.

There was a sense of feeling *hopeful* that the emphasis on working with seldom heard groups is increasing and more organisations are making it a priority. Feeling *safe* was also expressed by one attendee, as they felt totally comfortable engaging with people from different groups and communities.

Figure 1: Positive emotion cards



The most common negative emotion expressed was *annoyed*. Some attendees described feeling annoyed at what seldom heard groups had to go through to get the services they need, whilst other attendees felt this way towards the lack of resources available versus the high demand on focusing working with these groups. It was noted that the pandemic has added to this disparity causing a feeling of *disappointment* too. The effects of the pandemic were also noted when one attendee described feeling *overwhelmed*, they expanded on this by saying the increase in workload and safety restrictions in place because of Coronavirus meant they didn't have the time and resources to put into working with seldom heard groups.

Anxiety was widely expressed with numerous attendees saying they felt anxious about how they would be perceived when carrying out their work, and whether they would meet the expectations seldom groups might have of them. Others described feeling anxious about trying too hard to treat them differently and coming across as patronizing or condescending, this also led to feeling *worried*.

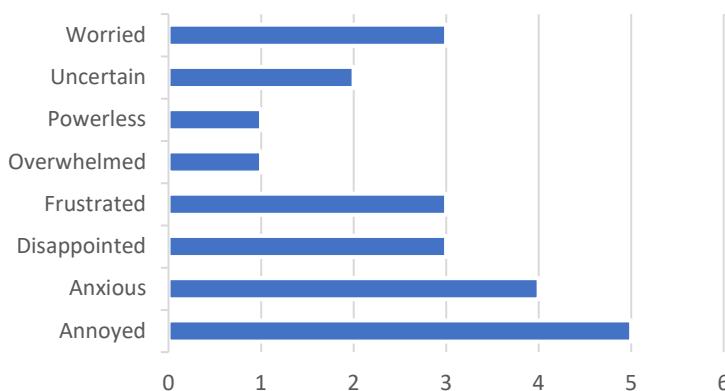
There was a recognition that there's no one right way of working with different groups which it itself made attendees express feeling *uncertain*. One attendee described feeling this way when starting a new piece of work, as they never knew what they might face or what difficulties they might run in to.

One attendee described feeling *powerless* as a reflection on how the different groups who they've worked with felt.

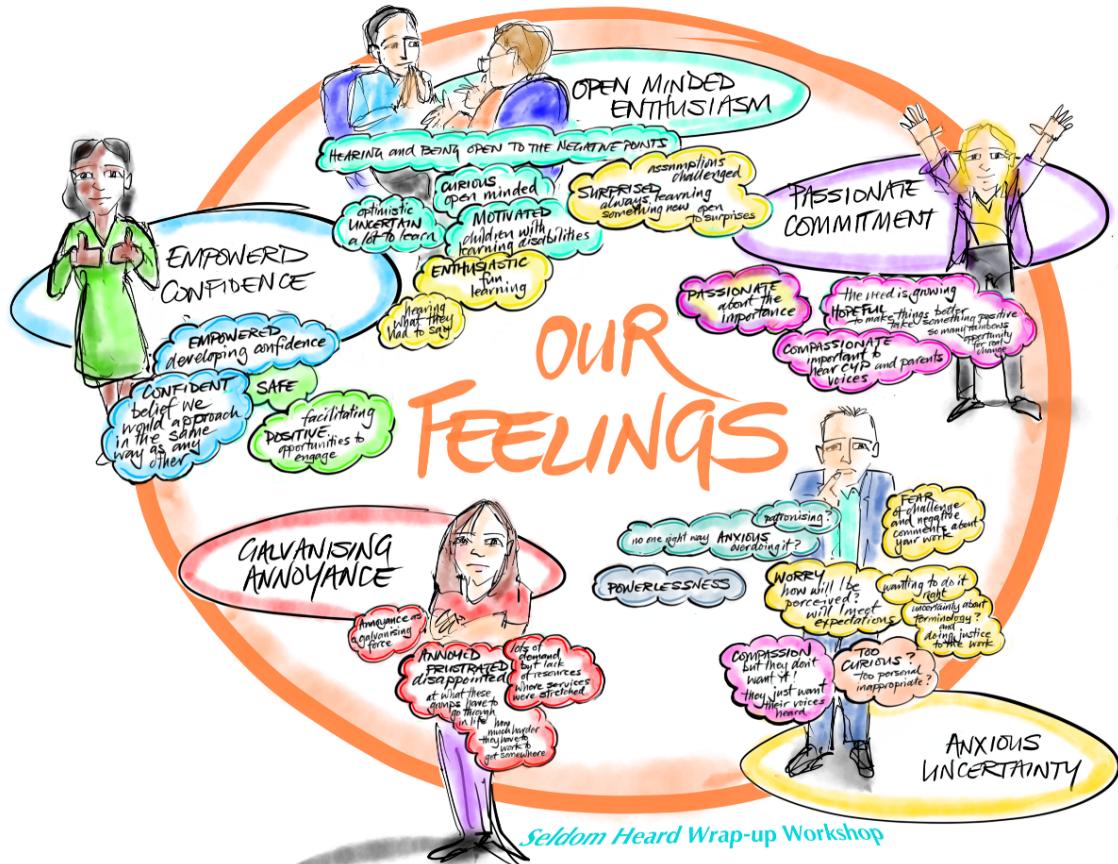
It is interesting to note a tension between the positive and negative emotions. Attendees feel positive, enthusiastic, and curious in an open minded way about the opportunity of working with seldom heard groups, whilst at the same time feel wary and anxious about being patronizing and turning compassion into pity, with the overarching pressure of wanting to do the work justice.

Whilst summarising this feedback session, we discussed how the negative emotions often come from a place of fear for being challenged or having negative comments said to you about your work. However, it was agreed that it is only by hearing and being open to these types of negative comments that you can move forward to continue to improve getting people involved.

Figure 2: Negative emotion cards



The following emotion cards were not selected by any attendees: calm, guilty, hopeless, stressed, tired.



Keynote listening by Creative Connection.co.uk

Session 2 – experiences of working with Seldom Heard groups

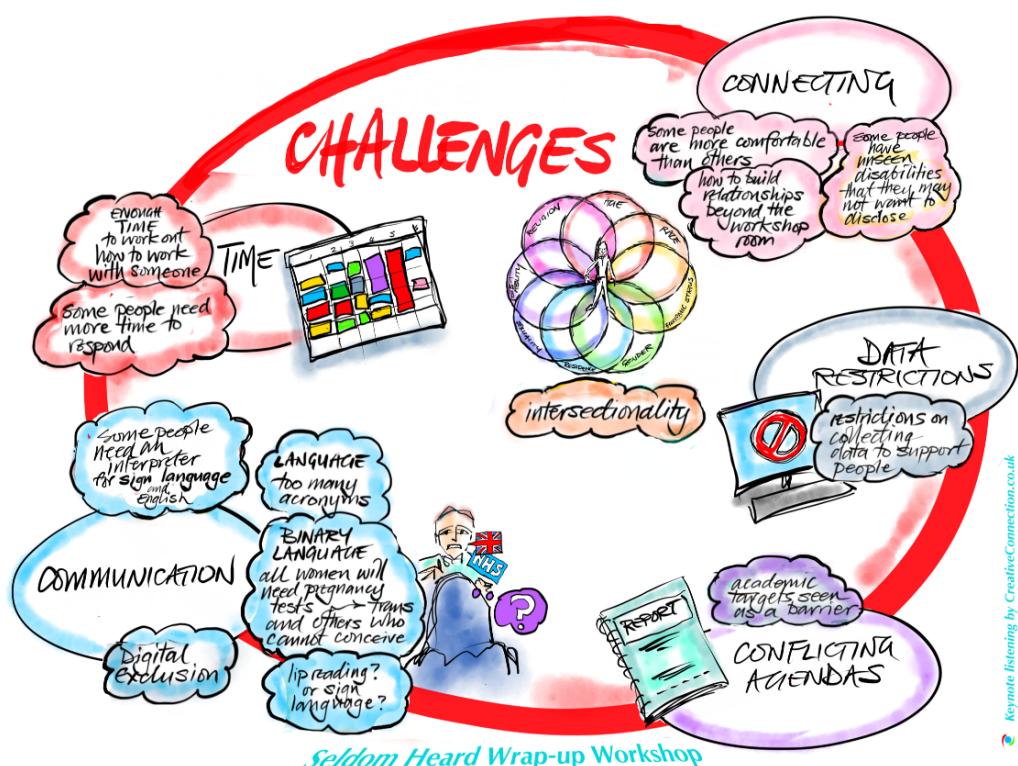
The second session asked the question: *what have been your experiences of working with seldom heard groups?* Prompt questions for this session included: what barriers got in the way? What worked well? Attendees were also asked to give hints and tips where possible. The facilitator from each group fed back their groups' comments which were noted on Zoom whiteboard for all to see.

Attendees remained in the same breakout groups as the previous session.

It was clear from the feedback that each group's conversation naturally fell into categorizing what does work (hints and tips) and what prevents work (barriers). Whilst there was some crossover in ideas, each group contributed unique suggestions, helping to produce a thorough list. It was noted that Coronavirus restrictions have introduced new issues, however some of the hints and tips outlined below were specially aimed at having to work within the pandemic restrictions.

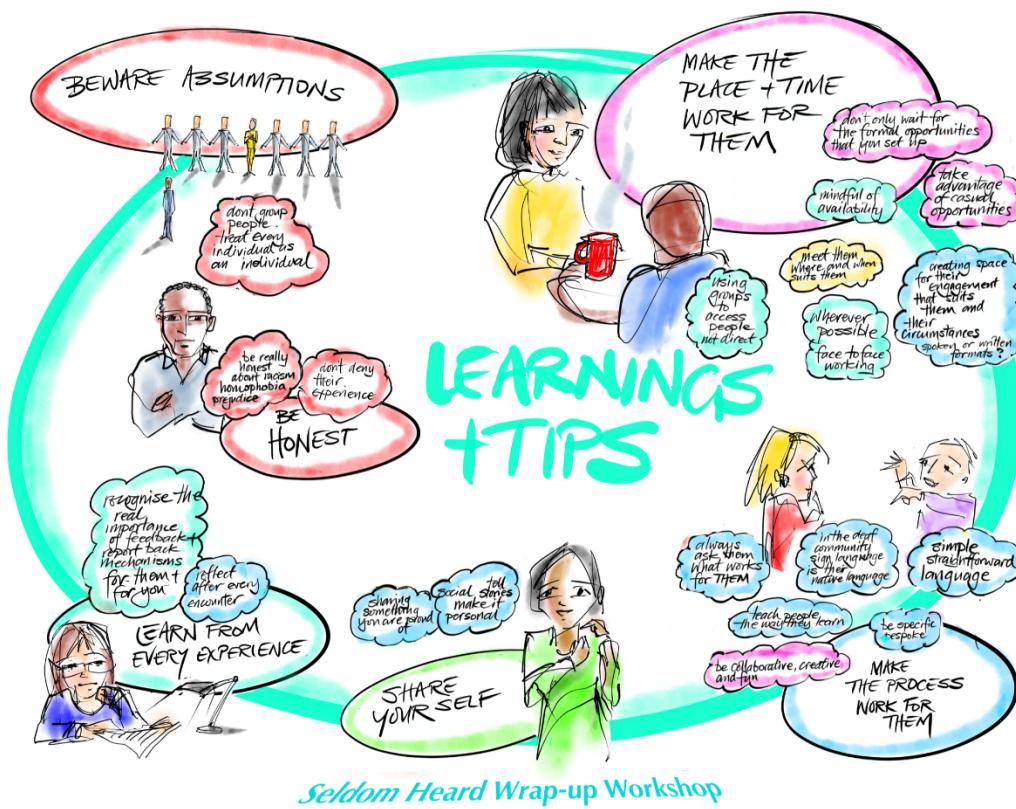
What gets in the way – barriers:

- Time constraints – it takes a lot more time to work with certain groups (e.g. those with dementia, learning disabilities) both in the pre-work and the meeting itself. The issue of time was identified as a barrier in all four breakout groups.
- Systemic issues – one group gave the example of IT systems only allowing you to choose 'male, female or prefer not to say' when selecting gender. This limits what data you can collect and how well you can support people. The need to bring in wider infrastructure to do this well was highlighted.
- Language – too many acronyms can be intimidating, and you need to include simple language in your work, whilst striking a balance and not being patronising. Binary type language can also be problematic.
- Seen vs unseen disabilities – it might not always be clear if someone has a disability, or how they identify with it (e.g. dyslexia). Therefore, you might not always think to tailor your work for them.
- Lack of general resource in this area of work – although there is hope that this will change as this area of work is becoming more widely discussed and recognised.



What works well – hints and tips:

- Use existing routes to access groups e.g. community groups. This helps make inroads in a positive and trusted way.
- Don't always wait for formal opportunities, if a casual opportunity arises to do some work with a group, then take it
- Be honest and upfront about the challenges that exist for the group e.g. homophobia, racism
- Always ask people what works for them
- Teach people the way they learn
- Go to places where people are already and tie your work in with activities that they are already doing
- When engaging with people online, be mindful of giving them the opportunity and space to engage when it works for them i.e. create/use a platform that allows people to log on and share their thoughts at any time of night or day. Also be considerate of technological barriers – in terms of both knowledge and access – when offering things digitally.
- Involve the groups in your planning where possible, especially younger people/children
- Reflect on your work and ask for feedback
- Ice breaker suggestion: sharing something with the group that you are proud of – it is personal and sets good tone for discussion



Session 3 – what next?

This final session asked the question: *how will this change what you do?* Attendees were asked to consider what they would stop doing, continue doing and start doing. The facilitator from each group fed back their groups' comments which were noted on Zoom whiteboard for all to see.

Attendees remained in the same breakout groups as the previous two sessions.

Once again, there were common themes and discussions that emerged from all four groups, with many expressing a positive and enthusiastic outlook on what they will and won't take forward in their work.

What will you stop doing?

- Thinking of people as groups
- Making assumptions that all individuals who sit within a seldom heard group think and feel the same
- Using labels

What will you continue doing?

- Insisting on clear and simple language. It helps be more accessible in our work and engage with different groups. Recognise that making language clear isn't easy and it takes time and input from lots of people.
- Keep talking about this subject and continuing to engage people/organisations who are currently uninterested in this area of work
- To keep eyes open to barriers and remain aware of them

What will you start doing?

- Trying to be more adventurous and not staying in comfort zones and using 'quick wins'
- Being more flexible with approach to work so that it suits the individual
- Doing things to make people feel that they belong, which in turn makes people feel comfortable, at ease and willing to contribute
- Introduce peer support groups
- Focus on feedback, ask if it is working? Do we need to introduce something new? Bearing in mind that people might not feel comfortable expressing this during a piece of work (focus group, chat etc.) so ensuring you give them the space to feedback on this afterwards is very important.
- Accessing more established routes
- Taking up opportunistic engagement
- Embedding the 'you said, we did' ethos

Two discussion points emerged, that didn't fit into either of the above headings. The first was the considerations of the pandemic restrictions, and how this will have an ongoing effect on our work. One group described the need to work as creatively as you can around the restrictions and offer wide variety of options to individuals, especially around communication. Linked with this, it was noted that considerations on digital exclusion were essential, and acknowledging that it could be putting another barrier in the way of existing communication issues.

The second point introduced the notion that problems faced by these groups was not a fault of their own, but rather a result of embedded systemic and cultural issues within organisations. It was suggested that work should be focused on tackling the problems within organisations, rather than working only with individuals within a group. Whilst there were not solutions given on this point, it was clear that it was a consideration that many attendees agreed on and would take forward in their work.



Working Together

Patient and public involvement in the Thames Valley

Working with the Seldom Heard



The LGBTQ+
Community



People with
Learning Disabilities

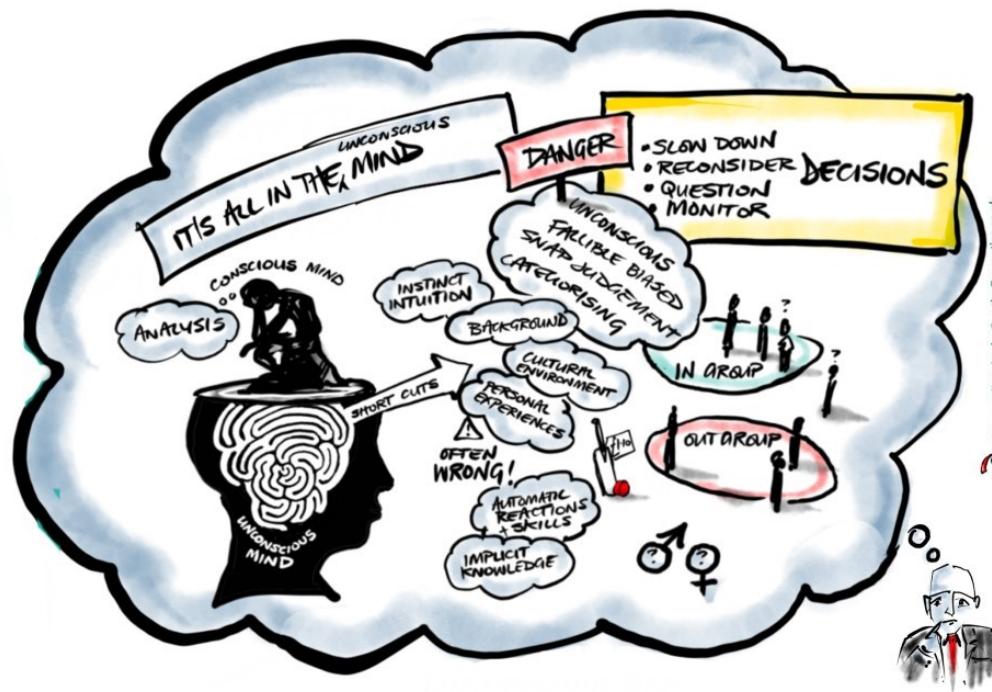


People with Sensory
Impairments

GETTING ON THE SAME PAGE

To provide some context to the discussions and speaker presentations that would take place during the events, we opened each of these webinars with a short clip from [The Royal Society](#) on unconscious bias. Professor Uta Frith, who wrote the introduction to the Royal Society clip says:

"Our unconscious brain is constantly processing and sifting vast amounts of information looking for patterns. When the unconscious brain experiences two things occurring together (e.g. many male senior managers or many female nurses), it begins to expect them to be seen together with the result that other patterns or combinations start to feel less 'normal' and more challenging to process. If left unchecked this can easily lead us into (at best) lazy stereotypes and (at worst) prejudicial or discriminatory behaviours"



Working with the seldom heard: Webinar report



The LGBTQ+ Community



INTRODUCTION

This webinar was the first in a series around the theme of ***Inclusion for all? Working with the seldom heard*** hosted by the [Working Together Partnership](#).

Hosts

Siân Rees – Director of Community Involvement & Workforce Innovation

Douglas Findlay – Lead Lay Partner

Laurie Kenny – Programme Coordinator

Speakers

Nicholas (Nic) Bray – Transgender Conduit

Georgia Pattison – Birmingham LGBT

Michael Farquhar – The Rainbow NHS Badge Scheme

Illustrations by [Creative Connection](#)

SPEAKERS

Nicholas (Nic) Bray – Transgender Conduit

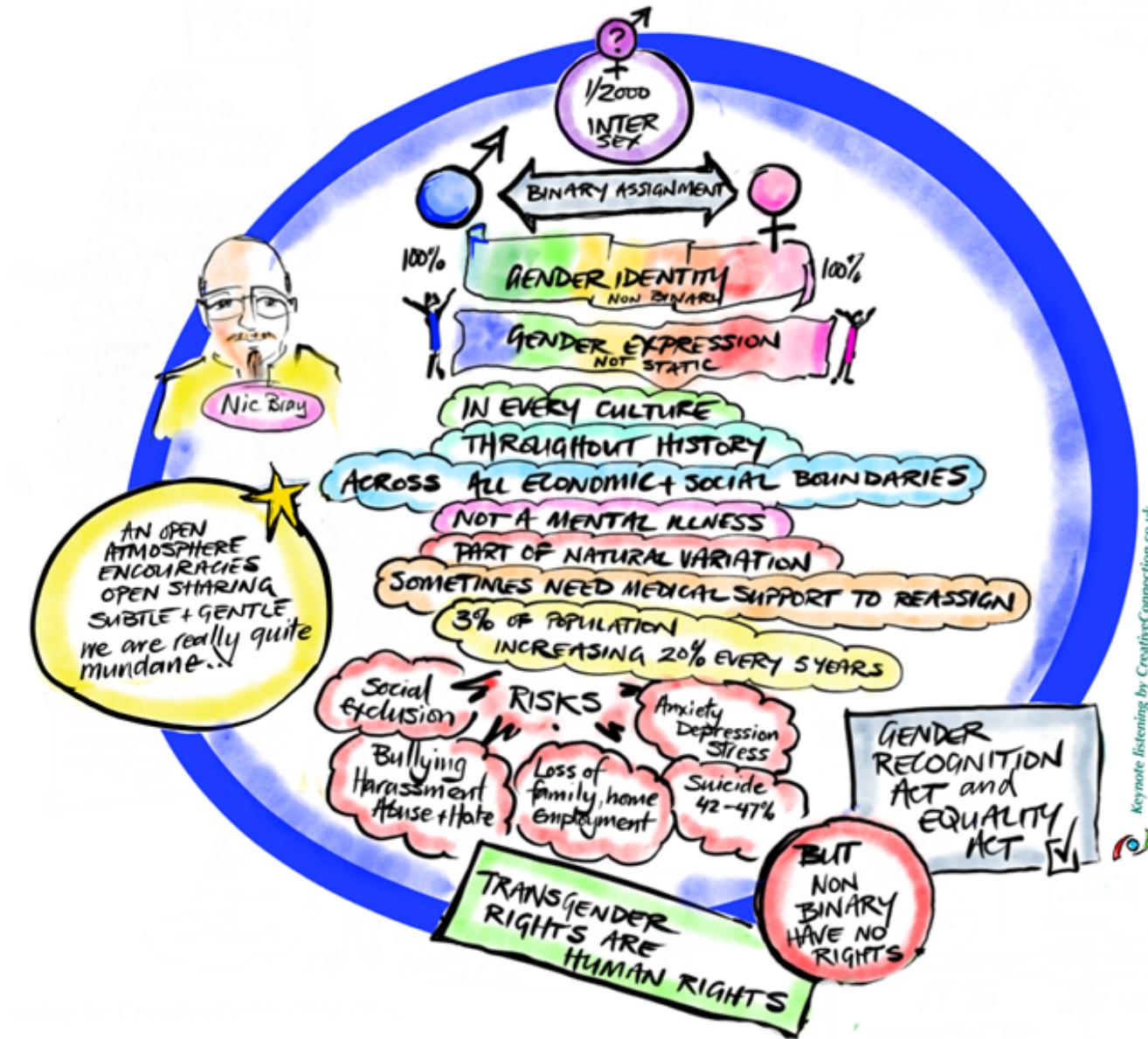
Our first speaker was Nic Bray aka Transgender Conduit. Nic has worked with the Working Together group in the past and was introduced to the group through its Leading Together Programme¹.

Nic covered the subject of working with people who identify as Trans & Non-Binary. He began with a few helpful definitions and myth busters, presented population data but cautioned us, reporting that accurate prevalence data is not yet centrally collected.

He went on to talk about the prejudice (and sometimes persecution) faced by people who identify as Trans & Non-Binary. Nic finished his reflections by outlining some of the more important pieces of legislation that have changed the lives of people who identify as Trans & Non-Binary. These range from the 1970 Corbett vs Corbett (outlines the qualification to be recognised as their new sex in the UK), through the 2010 - Equality Act (The Gender Equality Duty) and right up to date with the shelving of the **2020 - Gender Recognition Act revisions** in our current Parliament.

¹ The Leading Together Programme is a coproduction leadership course for patients, public and professionals, more information can be found [here](#)

Working with the seldom heard: the LGBTQ+ community



Georgia Pattison – Birmingham LGBT

Georgia is the Lesbian and Bisexual Women's Sexual Health Promotion Worker at Birmingham LGBT, grassroots, user-led organisation located within and accountable to, Birmingham's diverse Lesbian, Gay, Bisexual and Trans communities. More information on Birmingham LGBT can be found [here](#).

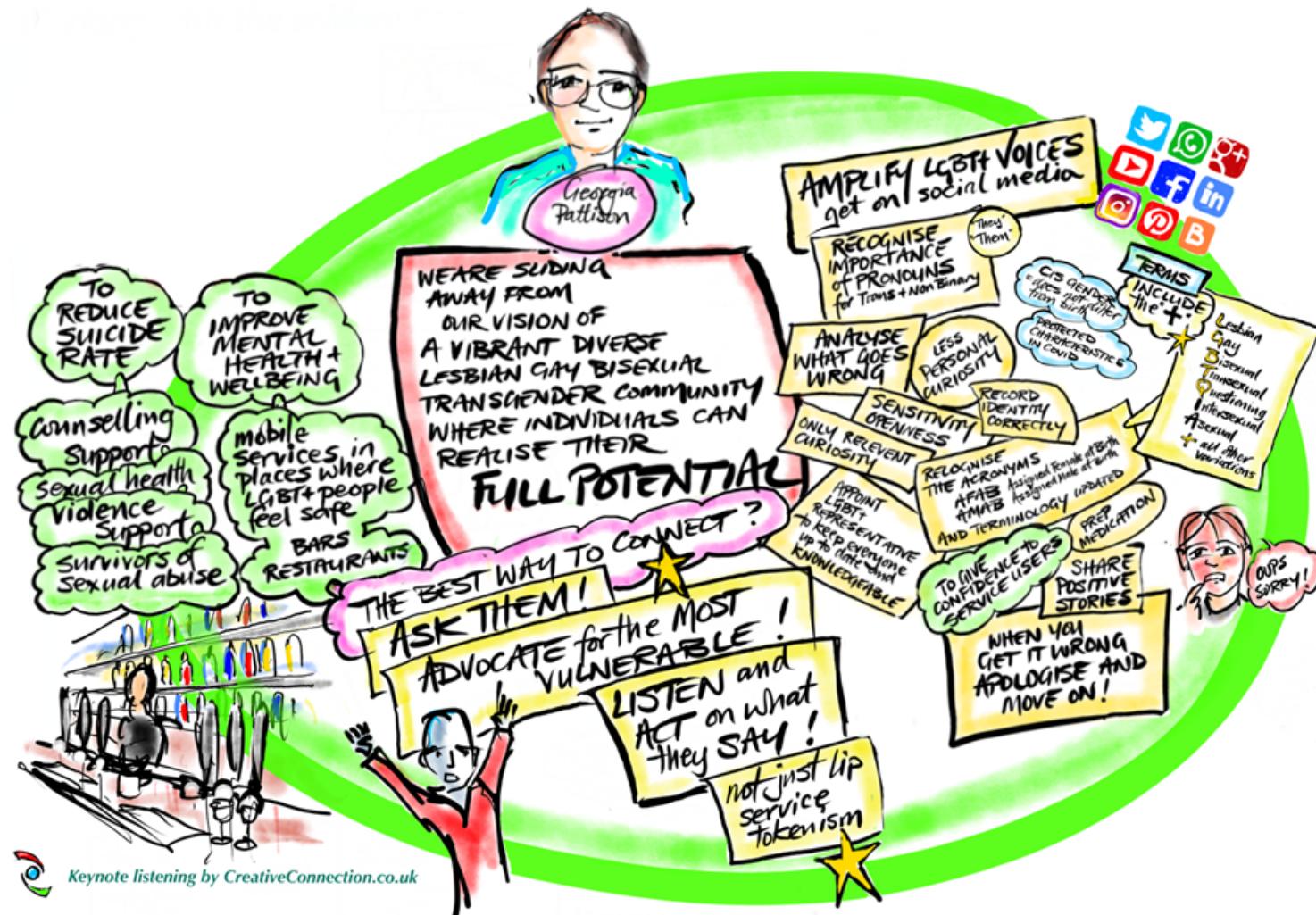
Georgia highlighted the importance of staff training within her talk, stating "knowledge is power" and that by ensuring staff are filled with the correct knowledge, it would hopefully give them the confidence to work collaboratively with the LGBTQ+ community. She also explained that unfortunately, too often, we only hear the bad experiences that LGBTQ+ people have with healthcare, but luckily within her work she does get to hear some positive stories in which the individual's life has been positively affected by the great healthcare service they have received.

Top Tips – Do

- Be mobile, use spaces where LGBTQ+ people feel safe, this will encourage them to engage with a service or piece of research. Go to the community that you are targeting/supporting.
- Amplify the voices of LGBTQ+ - ask local LGBTQ+ voices to be involved in the production of materials. Encourage social media takeovers on certain days of the year e.g. LBT Women's Health Week.
- Recognise the importance of pronouns - for some people this may be the only time they can truly be out and use their preferred pronoun. Use pronoun badges for staff, ask people what their pronouns are to avoid misgendering them. Pronouns such as they/them can feel very different at first but respecting an individual's pronouns is really important. Everyone gets it wrong sometimes but apologising and moving on is ok. If you are unsure of someone's pronouns, then use 'they' or address them by their name rather than using a pronoun.

Top Tips – Don't

- Start to shift around when the patient discloses their sexuality or gender identity.
- Asking questions out of personal curiosity, not professional need.



Michael Farquhar – The Rainbow NHS Badge Scheme

Dr Michael Farquhar is a Consultant in Sleep Medicine at Evelina London Children's Hospital, and he led the rainbow NHS badge scheme. More information on the rainbow badge scheme can be found [here](#).

Michael said that despite improving social attitudes in the UK, LGBTQ+ people can still face significant barriers to accessing healthcare and this can have a detrimental impact on physical and mental health. There are high rates of negative experiences, and of mental ill health amongst children and young LGBTQ+ people.

- 45% of LGBT+ children in school report being bullied for being LGBT+, 64% of trans pupils report bullying.
- High rates of attempted suicide in LGBT+ school children: 9% non-LGBT+ children, rising to 22% of LGB children and 45% of trans children. Rates of self-harm show a similar picture.
- 60% LGBT+ young people do not have an adult to confide in, in BAME groups this rises to 72%. Almost all found that having an positive role model made a major difference to them.

Wearing an NHS rainbow badge is a way for staff to show where they work is an open, non-judgemental and inclusive place for children, young people and their families who identify as LGBT+ and that we are here for them in every way. When staff sign up to wear one of the rainbow badges, they are provided with information about LGBT+ health inequalities and ways that they can help to tackle them, something Michael explained was very important. The initiative has already led to many extremely positive conversations and Michal went on to say that he really hoped that the toolkit they've designed will encourage other NHS organisations to introduce rainbow badges as they can play a valuable part in reducing stigma and inequality.

Michael finished his talk by saying that giving LGBTQ+ young people a simple, clear signal that healthcare professionals they may meet can be safe people to confide in can make a huge difference to them – the Rainbow Lanyard signifies this.

Working with the seldom heard: the LGBTQ+ community



Working with the seldom heard: Webinar report



People with Learning Disabilities



INTRODUCTION

This webinar was the second in a series around the theme of ***Inclusion for all? Working with the seldom heard*** hosted by the [Working Together Partnership](#).

Hosts

Siân Rees - Director of Community Involvement & Workforce Innovation

Douglas Findlay - Lead Lay Partner

Laurie Kenny - Programme Coordinator

Speakers

Dawn Wiltshire and Jess Tilling – My Life My Choice

Angeli Vaid – Oxfordshire Family Support Network

Rachel Miller – Oxford Health NHS Foundation Trust, Learning Disability Services

Illustrations by [Creative Connection](#)

SPEAKERS

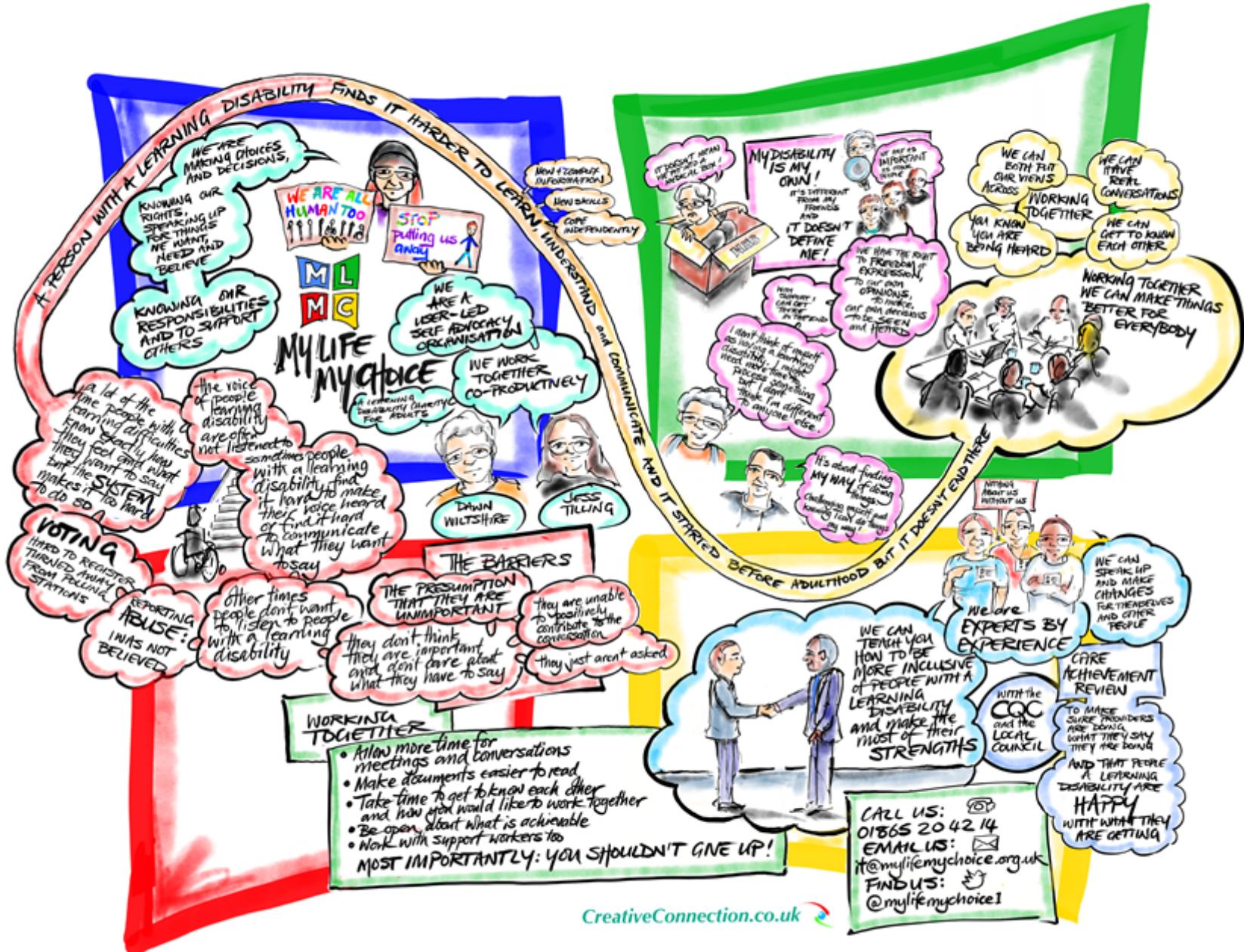
Dawn Wiltshire and Jess Tilling - My Life My Choice

Our first speakers, Dawn and Jess, were representatives from My Life My Choice, an Oxford based organisation working to help people with learning disabilities use their voices. They began by sharing the difficulties and barriers that people with learning disabilities face in their everyday lives. This included accessing services, making complaints and people making assumptions about them. Jess helpfully defined what constitutes a learning disability and these included:

- A significantly reduced ability to understand new or complex information
- Difficulty learning new skills
- A reduced ability to cope independently (impaired social functioning)
- Started before adulthood, with a lasting effect on development

Dawn followed Jess by giving some personal reflections on what having a learning disability meant to her and how being a part of My Life My Choice (MLMC) helped her and others with learning disabilities to have a voice. Jess picked up the theme of how The Law has developed to protect the rights of people with learning disabilities, citing **Article 10 of the 1998 Human Rights Act** and the **2006 Convention on the Rights of Persons with Disabilities**. These, as well as other laws have been passed to allow disabled people have the right to their own opinions and to make their own decisions. Both Jess and Dawn referred to 'Experts By Experience, as people who use their experiences to make changes for other people. An Expert By Experience is someone who understands what it is like and can speak up about it. Dawn concluded by pointing how she and her colleagues at MLMC have found working together with people who do not have learning disabilities has been really helpful in putting their views across and knowing that they had been heard. More can be found out [here](#).

Working with the seldom heard: People with learning disabilities



Angeli Vaid - Oxfordshire Family Support Network

Angeli Vaid is a Family Advocate at the Oxfordshire Family Support Network (OXfSN), a charity set up in 2007 and run by family carers of people with learning disabilities – both children and adults. OXfSN provide information, advice, training and support to family carers of people with learning disabilities and cover all ages. They also support professionals in healthcare and social care to work better with families through training, co-production and partnership working. More can be found out [here](#).

Angeli then gave specific examples of the types of clients of all ages and from a variety of backgrounds that they work with, pointing out their ‘family’ situations and their preferred methods of communicating with others (including professionals).

Angeli also outlined what family carers often think about before signing up with OXfSN, which gave us a lot to think about, as it included – being seen as difficult or as a tick in a box, or that nothing would change – thankfully, she also gave us ways of addressing these hurdles. Angeli’s final slides gave us hints and tips on what to do and what to avoid.

Top Tips - Do

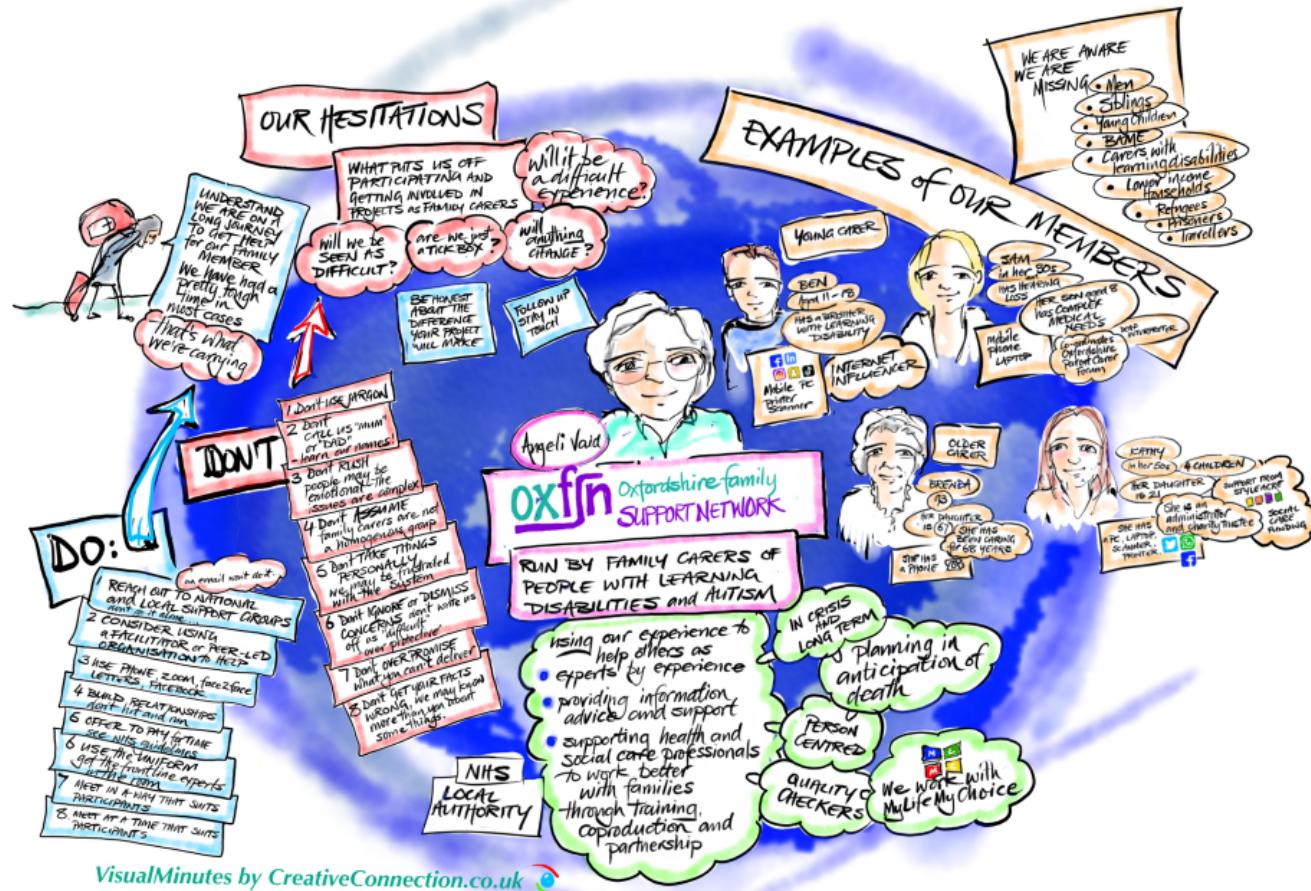
1. Reach out to national and local support groups – don’t go it alone
2. Consider using a facilitator or peer-led organisation to help
3. Use the telephone, Zoom, face2face, letters, FB,
4. Build relationships – don’t hit and run
5. Offer to pay for time – see NHS guidelines
6. Use the uniform- get your experts in the ‘room’
7. Meet online, off-site, in the evening, at weekends, community centres, cafes, golf courses, wherever suits the participants
8. Timings – school run, holidays - not good

Top Tips – Don’t

1. Jargon, acronyms - confusing and imbalance of power
2. ‘Mum’ or ‘Dad’ - learn names
3. Rush - people may be emotional, the issues are complex

Working with the seldom heard: People with learning disabilities

4. Assume - family carers are not a homogenous group
 5. Take things personally - frustration and anger is with the system
 6. Ignore or dismiss concerns – ‘difficult parent’ or ‘over-protective’
 7. Over promise on what you can’t deliver
 8. Get your facts wrong – family carers often know their onions



Rachel Miller - Oxford Health NHS Foundation Trust, Learning Disability Services

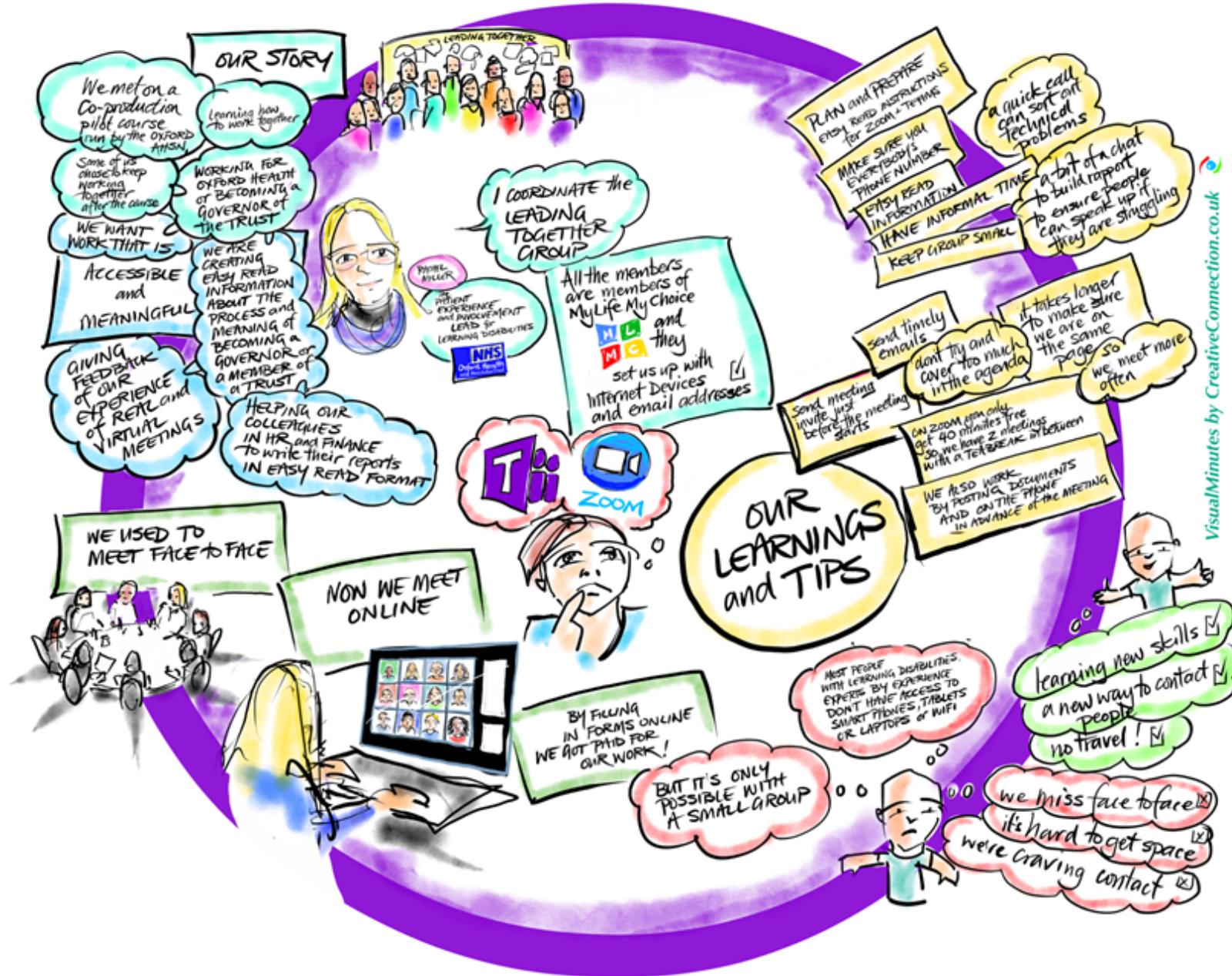
Rachel is the Patient Experience and Involvement Lead at Oxford Health NHS Foundation Trust that provides physical, mental health and social care for people of all ages across Oxfordshire, Buckinghamshire, Swindon, Wiltshire, Bath and North East Somerset. More can be found out [here](#).

Rachel told us about a project called the Leading Together programme – a co-production course run by Oxford Academic Health Science Network. The programme brought together pairs, consisting of a person with learning disabilities and a senior NHS professionals, to support them to learn the principles of co-production. There were many things that everybody learnt about how to work together successfully.

Rachel then gave us an insight into how Covid-19 has changed the ways in which people in the Trust (both professionals and service users) have had to adapt working practices and the challenges that this has brought up. Mostly it was finding new ways to meet, that involved teaching service users how to use communication technologies (and sometimes providing the hardware). Rachel gave the following top tips:

Top Tips

1. Plan and prepare well in advance think broadly about what service users might need or struggle with.
2. Numbers – always have contact numbers, in case things don't go to plan or technology fails.
3. Easy read - provide easy read instructions and documents being used.
4. Informal time - build in informal time to touch base and make the experience as stress free as possible.
5. Contact Information- provide good and accurate contact information



Working with the seldom heard: Webinar report



People with Sensory Impairments



INTRODUCTION

This webinar was the third in a series around the theme of ***Inclusion for all? Working with the seldom heard*** hosted by the [Working Together Partnership](#).

Hosts

Siân Rees - Director of Community Involvement & Workforce Innovation

Douglas Findlay - Lead Lay Partner

Laurie Kenny - Programme Coordinator

Speakers

Sally-Jane Davidge – Governor, Oxford University Hospitals NHS Foundation Trust

Chris Harrison – Action Deafness

Chrissi Kelly – AbScent

Illustrations by [Creative Connection](#)

SPEAKERS

Sally-Jane Davidge – Governor, Oxford University Hospitals NHS Foundation Trust

Sally-Jane Davidge describes herself as a “VIP” – a visually impaired person. She completed the Leading Together Programme in 2017 and is a governor at the Oxford University Hospitals Foundation Trust, representing patients and their carers in Buckinghamshire, Berkshire, Wiltshire and Gloucestershire. She is currently chair of the governors' committee for patient experience, membership and quality.

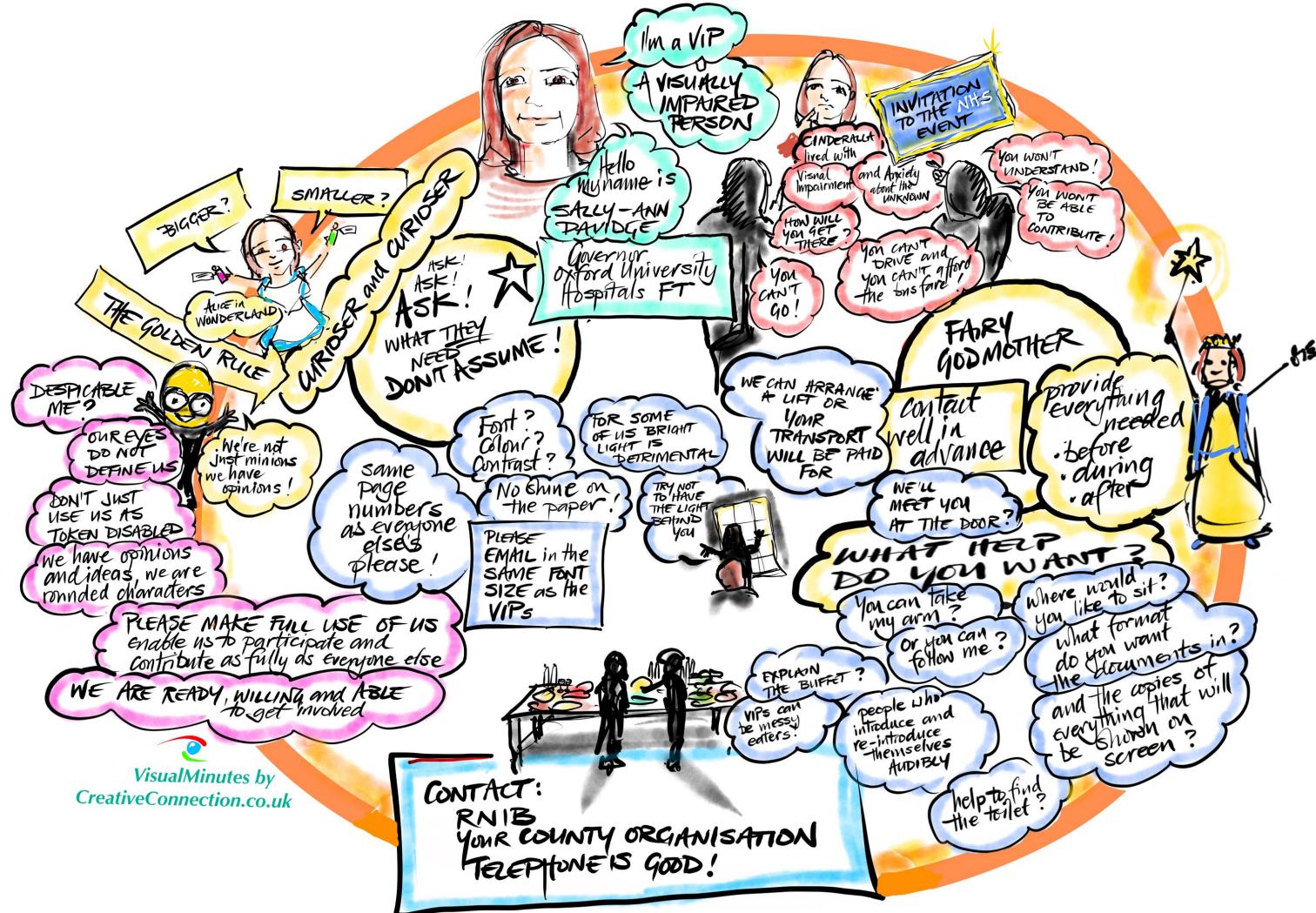
Throughout her humorous presentation, Sally-Jane endeavoured to attract attention to the many challenges a visually impaired person faces when trying to attend an NHS event. From the practicalities of getting to the event, to how the day might unfurl and what sort of assistance might make a difference.

Top tips – Do

- Ask people what they need and what would make their life easier
- Contact the person in advance with all practical information
- Make sure you make it as easy as possible for them to physically attend
- Adapt the material to visually impaired attendees and send everything in advance
- Ideally make sure somebody is available to accompany them during your event
- Make full use of your VIP – their disability does not impair their ability to think and contribute

Top tips – Don’t

- Use them as your “token disabled person”
- Expect them to be able to read everything on a screen
- Assume they won’t make as valuable a contribution as everyone else



Chris Harrison – Action Deafness

Chris is the Service Manager for deaf-led charity [Action Deafness](#). For over 120 years Action Deafness has been providing support for Deaf, Hard of Hearing, Deafened, Deafblind people and those with additional disabilities, with the strong belief that every person has the right to live with dignity, equality, comfort and independence. The charity provides interpreters, translators, equipment, support, personal assistance and other services adapted to every kind of hearing disability.

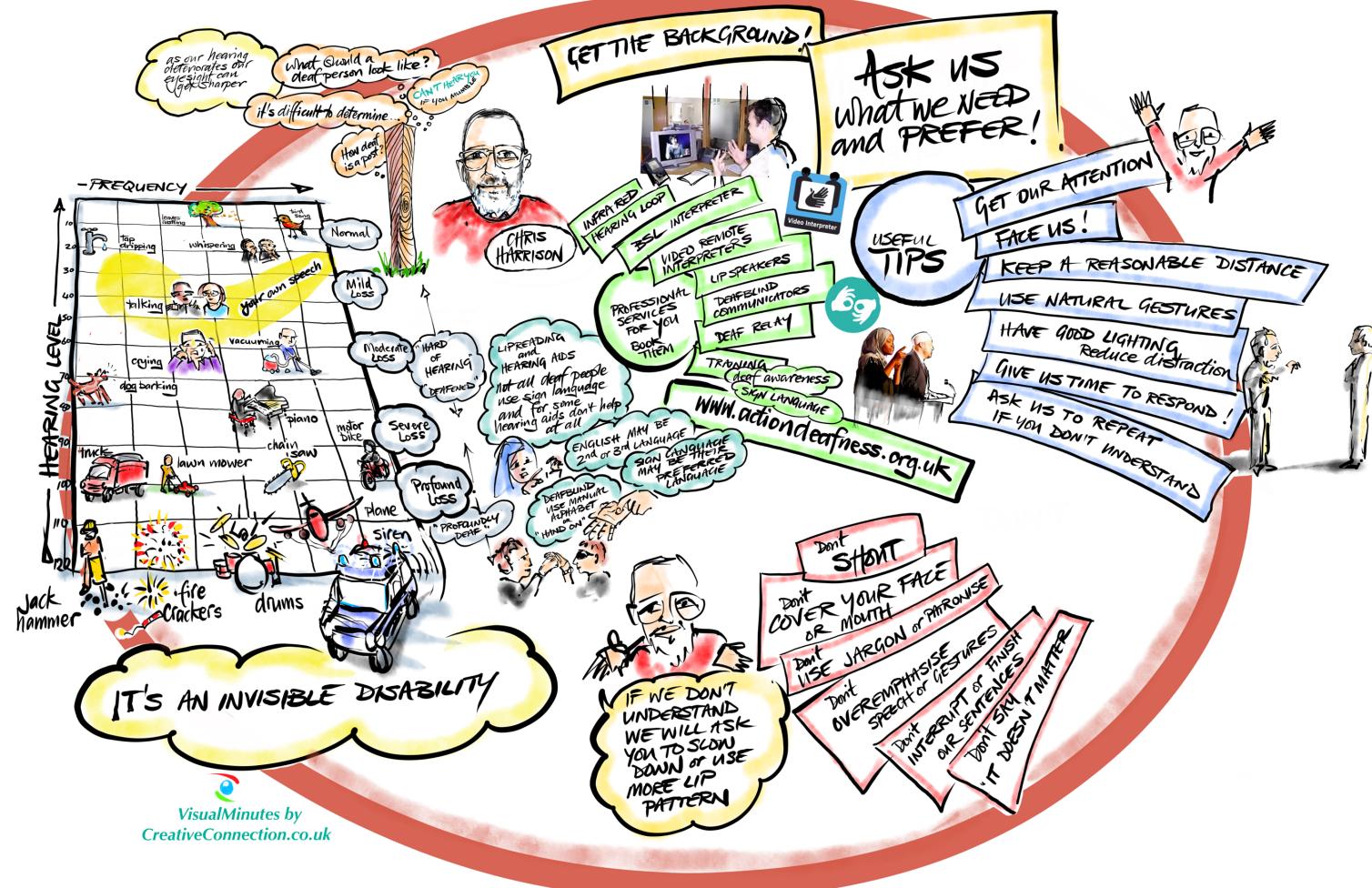
Chris is a qualified BSL Interpreter and trained Benefits Adviser. He has worked for educational establishments and in the voluntary sector as an employment adviser and employment manager.

Top tips – Do:

- Get the deaf person's attention
- Face the person
- Keep a reasonable distance
- Use natural gestures and body language
- Have good lighting and reduce distraction
- Give the person time to respond
- Ask them to repeat if you don't understand

Top tips – Don't

- SHOUT
- Cover your face or mouth
- Use jargon or patronise
- Over emphasise speech /gestures
- Interrupt or finish the person's sentences



Chrissi Kelly – AbScent

Chrissi lost her sense of smell in 2012. She is a founding member of the charity [AbScent](#).

AbScent is a charity registered in England and Wales, providing support and trusted information to anyone affected by anosmia or smell disorders. Supported by their advisory board and led by Trustees currently working in the fields of medicine and research, it makes a point of only sharing strategies and information based on peer-reviewed scientific evidence. They endeavour to create safe and supportive environments to enable their members to feel heard and enabled by shared experience. Information, current research updates, webinars, advice and support on their website and within their Facebook communities is provided free of charge and is open to everyone. Public interest in loss of smell and taste has grown immensely since the start of the Covid-19 pandemic, creating huge opportunities and challenges for the charity. In particular, research into the causes, consequences and possible treatments for anosmia has been given a huge boost.

Since losing her sense of smell Chrissi has supported thousands of other people with smell loss through smell training. She has taken courses with Professor Thomas Hummel, the author of the first research paper on smell training at the University of Dresden, Germany. Her techniques, used alongside smell training kits, have helped people to reconnect with their recovering sense of smell. Chrissi also speaks at conferences, runs workshops, online events and private sessions to support people with the condition.

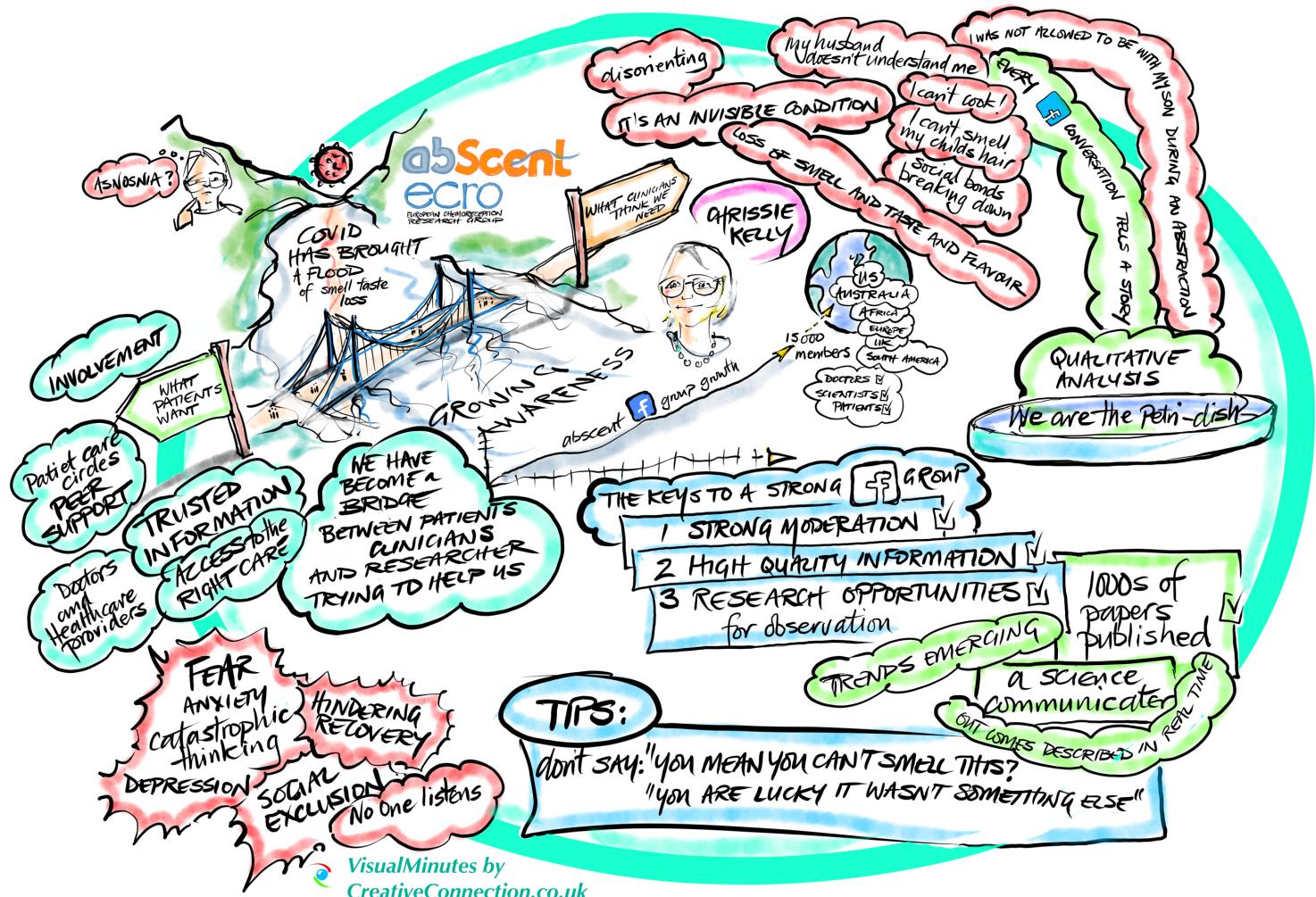
Chrissi focused on her journey, successes and challenges founding AbScent and seeing it develop beyond anything she had imagined.

Top tips – Do:

- Acknowledge the fact that this is a distressing condition despite being invisible
- Listen to people's experience
- Only follow reliable information

Top Tips – Don't

- Minimise the condition – “At least you *only* lost your smell”
- Assume people's sense of smell will come back



BRIEFING PAPER

SELDOM HEARD WRAP-UP WORKSHOP

THURSDAY 29 APRIL 2021, 10am – 1pm



BACKGROUND TO WORKSHOP

Ensuring that health services, research and education meet the needs of people from all walks of life is vital. To achieve this, we need to work in partnership with people from diverse communities, for example Black, Asian & Minority Ethnic groups or the LGBTQ+ community. This often means we need to work differently: going to different places, meeting people where they are. At the end of last year, we held three online webinars (see below) where we heard from a range of speakers from different communities.

LGBT+ Community, 2 November 2020

Learning Disabilities, 19 November 2020

Sensory Impairments, 7 December 2020

The recordings of all three webinars from last year can be viewed [online here](#), and a combined PDF report from each event can be found as a separate attachment to this email.

These events are organised by the Working Together Thames Valley Partnership:

[Oxford Academic Health Science Network \(AHSN\)](#)

[NHS England South East](#)

[NIHR Oxford Biomedical Research Centre \(BRC\)](#)

[NIHR Oxford and Thames Valley Applied Research Collaboration \(OTV ARC\)](#)

[NIHR Oxford Health Biomedical Research Centre \(BRC\)](#)

[NIHR Clinical Research Network Thames Valley and South Midlands](#)

PURPOSE OF WORKSHOP

This workshop aims to build on what we learnt from last year's webinars, whilst providing the opportunity for participants to reflect and talk with other people to share challenges and ideas. We will encourage all participants to consider:

- What did we learn?
- What gets in the way?
- What will we do?
- What support might we need?

PRE-WORK – EMOTION CARDS

We would really like to hear your thoughts and feelings on working with Seldom Heard groups. Before you join, we would like you to consider the following question: *When thinking about working with Seldom Heard groups, what emotions come to mind?*

Please look at the following emotion cards (12 positive and 12 negative) and select **one positive** and **one negative** card that best describe how you feel in response to the above question. We will be sharing and discussing answers in small breakout groups within the workshop.

Positive Emotion Cards



Negative Emotion Cards

