



**THE 10-YEAR HEALTH PLAN
WORKSHOP FINDINGS, 7TH FEBRUARY 2025**



INTRODUCTION



About Alström Syndrome UK



Alström Syndrome UK (ASUK) was established in 1998 and is a registered charity providing information and support to individuals and families affected by Alström Syndrome (AS) and to the service providers working with them. ASUK works in partnership with Birmingham Women's and Children's Hospital and the Queen Elizabeth Hospital, Birmingham to deliver a highly specialised service, funded by NHS England. As a patient led organisation, the needs and wishes of people living with AS remain at the heart of everything we do. We aim to; provide personalised support, raise awareness, conduct pioneering research, and enable better treatments and monitoring through the AS multi-disciplinary clinics.

ASUK co-founded Breaking Down Barriers in partnership with The Sylvia Adams Charitable Trust.

About Breaking Down Barriers



Breaking Down Barriers is a network of over 70 organisations providing support to people affected by rare and genetic conditions. We work together to learn, develop, and share good practice. Promoting equity, diversity and inclusion is at the centre of what we do. Our Experts by Experience Advisory Group help us to understand the lived experiences of people from diverse, marginalised and under-served communities living with rare and genetic conditions. We create safe spaces for learning and collaboration, deliver training, contribute to research and run a community outreach project. We unite and strive for equitable access to services and support for all.

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Breaking Down Barriers (BDB) and the Department of Health and Social Care (DHSC) have been working together to make sure health equity is addressed within England's Rare Diseases Action Plans, following the publication of the UK Rare Diseases Framework.

The UK Rare Diseases Framework was published in January 2021, setting out a national vision on how the UK will aim to improve the lives of people living with rare conditions. The Framework was developed based on the findings from the National Conversation survey which was launched by Baroness Blackwood in November 2019. 6,293 people responded to the survey, including over 5,000 patients, families, and patient organisation representatives.

There are 4 key priorities and 5 underpinning themes, and each nation of the UK developed an Action Plan to show how these priorities will be met.

4 Key Priorities

- Helping patients get a final diagnosis faster
- Increasing awareness of rare diseases among healthcare professionals
- Better coordination of care
- Improving access to specialist care, treatments, and drugs

5 Underpinning Themes

- Patient voice
- National and international collaboration
- Pioneering research
- Digital, data and technology
- Wider policy alignment

When producing England's Action Plans, work has been carried out by England's Rare Diseases Framework Delivery Group to understand the health inequalities experienced by people affected by rare conditions, and to identify ways to address this through specific actions.

Since 2021, BDB and DHSC have worked in partnership to run workshops and focus groups to understand the health inequalities experienced by people from diverse, marginalised and under-served communities, who are also affected by a rare condition.

Reports and recommendations can be found on the BDB website:

[Health-Equity-Focus-Group-Report-Dec-22-Final.pdf \(breaking-down-barriers.org.uk\)](#)

[Health-Equity-Focus-Group-Report-Nov-23-FINAL.pdf](#)

THE 10-YEAR HEALTH PLAN WORKSHOP



In February 2024, BDB and DHSC worked in partnership to deliver a workshop as part of the government's consultation on the new 10-Year Health Plan. The aim of the workshop was to include the voices of people from diverse, marginalised and under-served communities who also have experience of living with rare and genetic conditions. The consultation focussed on the 3 key shifts within the plan – Analogue to Digital, Hospital to Community and Treatment to Prevention.

The workshop included a diverse group of 10 people with lived experience. 9 people joined the virtual workshop, and 1 person provided written feedback - their comments were shared during the discussion. Representatives from BDB, DHSC Rare Disease team and the 10-Year Health Plan team joined the workshop. The focus group was chaired by Kerry Leeson-Beevers, CEO of ASUK and BDB and patient representative on England's Rare Diseases Framework Delivery Group.

Preparation

In preparation for the meeting, workshop participants were provided with a brief explanation of each of the 3 key shifts:

Analogue to Digital – this means how to use better technology in health and care.

This could include using things like computers, smartphones and tablets. Technology could help you get care more quickly and could send out text messages to remind you about appointments. Technology could also be used to share information with other people involved in your care.

Hospital to Community – this means moving some care from hospitals to communities.

This could include you having more tests, scans, treatments and therapies nearer to your home (such as at the GP practice or pharmacy).

Treatment to Prevention – this means doing more to stop people getting ill.

This could mean having tests to see if you have a condition before you get ill. It could include advice about things such as healthy eating and information about how to live a healthy life.

Workshop participants were also asked to consider the following questions:

- What do you think about these three changes?
- What could work well?
- What do you think the challenges are going to be?
- Do you have any examples that you would like to share?
- Do you have any concerns?
- Do you have any ideas about what could work well?

Virtual Workshop

Following welcome and introductions, a member of the DHSC 10-Year Health Plan team introduced the 10-Year Health Plan and explained each of the 3 key shifts. Workshop participants were invited to ask any questions and to share their thoughts.

ANALOGUE TO DIGITAL

Workshop participants were positive about the way technology has advanced and how it currently supports them in their daily lives, from screen readers to mobile phones. However, they also raised some concerns and challenges.

The discussion centred around the need to get the right balance between digital and analogue. With technology moving at such a fast pace, the concern is whether everyone will be able to keep up. If not, there is a risk that this shift could widen the health inequalities gap and create even more digital exclusion for some people. Examples include people being excluded from being able to access their healthcare records and challenges with even being able to book a GP appointment.

The way that technology was introduced during the COVID-19 pandemic was shared as a positive example. During this difficult period, the NHS implemented a range of digital and technology-focused alternatives to delivering in-person healthcare.

People living with rare conditions often access a range of different services including health, education, social care and the benefits system. Organisations often don't talk to one another. People regularly need to provide documents to prove their identity and a summary of their health conditions and disabilities when claiming benefits, bus passes or a blue badge. This will be challenging without paper copies.

KH explained how his father used a smartphone for the first time during Covid. He described the challenges of having to support an elderly relative with technology. Paper is so important to many individuals.

AS talked about the need to be able to transfer information between devices, as this is often very difficult to do when you get a new phone or device.

HH discussed how accessibility issues would increase with the introduction of more technology. There are already accessibility issues with technology which are unresolved such as access to hospital systems and healthcare records. One suggestion was to include people with lived experience at the start of the development process to make technology accessible, and not as an afterthought once the technology has been rolled out. Also, providing enough support for those who need it when the technology is implemented so people feel confident to use it.

“My Son is blind and excellent at managing his condition. NHS systems aren’t integrated. I can’t understand why this hasn’t been resolved yet. How seriously are NHS trusts implementing accessibility standards? Allowances should be made for those with progressive conditions - for example, if they miss appointments they don’t go to the back of the queue.” – KH

KLB shared concerns that independence and autonomy may be taken away from some people as they find themselves needing support and assistance to manage appointments and their personal, confidential health information.

HH also shared concerns about language, particularly for people who do not speak English as a first language. Barriers already exist with in-person communications, this could be even more challenging when expected to use more technology.

LF suggested digital technology could be helpful if it has accessible and accurate language translation facilities.

It is important to consider the impact of new technology on low-income families who may not have access to smartphones or Wi-Fi. Digital poverty already exists and rolling out a technology led health care system that is dependent on being able to own and access technology, may leave some families at an even further disadvantage.

“There is no one size fits all, we need to make sure vulnerable people aren’t left behind.” KH

SH said she considers herself to be tech-savvy but often tech apps can be stressful to work out. It is stressful not having immediate access to medical records when on the phone to the doctor’s surgery. All technology and apps need regular updates too and can be very difficult to manage when you change devices.

JG said people may have concerns about data protection when using online platforms to receive their letters, so it would be important to address this. There may be challenges ensuring that all patients have the opportunity to access this, for equity of care.

DS felt it was important to note that he feels there are lots of benefits to technology and not just concerns. However, he is really concerned that AI will widen healthcare disparities and inequalities. What will be done to mitigate this? He explained how he gets a sinking feeling as a patient when hearing about the switch to digital. He has lost confidence in the current transition to digital in relation to his diagnosis with ME. There is little understood about his condition, and he is concerned that he will lose the face-to-face relationship with his GP.

LF would like to see scope for education around the switch to digital. Centralised information is beneficial but it's a process and people need support. The example given was the introduction of the Covid app and how this had issues and people lost trust. Technology doesn't always work and can have glitches. How do we build trust in this switch? LF explained that her local NHS Trust uses the 'Dr Doctor' system, and she described the issues of having to log in each time when you have multiple appointments.

“I still feel like I'm having to repeat myself hundreds of times to different healthcare professionals even though I'm using the app already!” – AH

SR agreed and added that technology can be very intrusive which is an issue for those with multiple appointments under multiple departments. Historic scans go missing if people move about. How can we make sure that data isn't lost?

SR also stressed the need to be aware that technology can improve services but doesn't replace face to face care which so many people feel they aren't getting already.

JG said it may be useful to have more digital ways of reaching healthcare teams (in a regulated way) or receiving letters on a digital platform, so that it is in one place. For a patient who has many appointments, it may be difficult to have paper records of letters and keeping them safe in one place. Moving towards a digital platform that is offered to patients, whilst still being inclusive of those who cannot access the internet or do not feel confident using technology.

HOSPITAL TO COMMUNITY

Workshop participants agreed that going to the hospital can be very stressful. This includes issues such as not being able to park, long waiting times and overcrowded departments. It was felt that community care could have a positive impact on people's experiences and patient care.

Both hospital and community healthcare teams need to understand the complex nature of rare and long-term health conditions. They also need to be aware of how culture and beliefs can impact a person's health, support systems and the choices they make. Healthcare services need to be provided in a safe and accessible environment and supportive of our multi-cultural society.

It is important to recognise that some languages don't have a translation for some of the health terms and words that we use, for example the word 'gene'. The group also shared examples of supporting families who felt a huge sense of blame and shame for the health conditions they live with. This can have a significant impact on their health and emotional wellbeing and on how they access and engage with services.

Participants discussed the impact of trust and stigma and how working with trusted community leaders can help support positive integration, build trust in services and promote effective communication. This was demonstrated during the Covid-19 pandemic.

KLB shared examples of how Community Champions have been very effective in helping to share key messages within communities. She feels it is important that they receive training to

understand different health conditions and disabilities. The community and voluntary sector are ideally placed to support the shift from hospital to community, but this should not be expected to be done on a voluntary basis or just for short periods and then be forgotten about.

HH suggested that training and awareness is needed on different conditions in different communities. He feels that some communities aren't aware of how to support people with certain conditions and disabilities. He said that people in his local community have had to learn how to support him to access local services.

“Strengthen the community and change perceptions, to get the best out of people and help each other rather than relying on healthcare.” – HH

LF shared that in some communities, there can be over familiarity with people overstepping boundaries. Self-diagnosis can also prevent people from accessing professional help and advice from healthcare professionals may be dismissed or avoided. Beliefs are often generational and won't change overnight.

Privacy may be an issue in community settings as people may be familiar with the healthcare staff.

Workshop participants discussed how challenging it already is to access community healthcare services, such as getting a GP appointment and accessing the correct medication.

LF shared her experience of regularly needing stronger pain killers to manage her painful chronic condition. Rather than the pharmacy being able to help, she is often told to try and get a doctor's appointment and regularly ends up in Accident and Emergency (A&E) when all other avenues had failed. This is so difficult, especially when you're already feeling unwell. Could there be links to private care in situations like this to reduce waiting times for people with rare conditions?

AS feels even getting to hospital is stressful and delays caused by trying to find somewhere to park can sometimes mean you nearly miss your appointment. It is also now really difficult to get medication, it used to be easier, but prescriptions now need to be ordered well in advance and sometimes they are not available.

JG suggested ensuring that the GP/pharmacy/community nurses are trained to deliver the same level of care and that they have the appropriate equipment to deliver this safely. For example, when she was being treated for Hodgkin's Lymphoma, she was primarily undergoing chemotherapy via a PIC line in Birmingham. However, due to an emergency she went to a hospital nearer to her home, but there was not a trained nurse at that time to use the PIC line to administer the medication or to clean the PIC line.

SH would like to know if there will be equal access to community services in each community or if it will be a postcode lottery. She is also concerned that in a small community, people may know more about you than you're willing to share and felt this could raise safeguarding issues.

SH also feels there are benefits to community services such as shorter waiting times. She shared an example of her husband being able to have a scan done more quickly by having it done at their local health centre. However, some community centres have additional burdens because services

are not being provided equally. She also has concerns about second class healthcare in the community vs a hospital.

SH feels there needs to be better understanding of the impact that living with a rare and complex condition has on people's lives. Things like childcare, work, care needs and numerous appointments – people are often penalised due to these responsibilities and challenges.

KH feels it is important to manage expectations. Some people believe that only bigger hospitals can cater to their needs. Those with multiple appointments may benefit from the move into the community. He also highlighted the regional differences in care.

KH shared examples of services that could be developed further such as social prescribing. He also suggested learning from local services in Bradford where local, culturally, sensitive services are supporting elderly people with falls and helping to prevent hospital admissions. We need to find ways to support and utilise grassroots organisations.

KH and *KLB* shared how both of their son's avoid A&E admissions whenever possible. They both find that the advice from Dr's and 111 operatives is to go to A&E once they describe their rare condition. They believe this is due to a lack of confidence and knowledge about the condition. It may also be a case of being risk averse and worried about governance and litigation. As carers, *KH* and *KLB* often know, that all their sons need is a course of antibiotics and that they are often put at further risk by waiting in A&E for long periods of time.

KLB described how her son feels that every time he visits A&E, he is likely to be admitted as a precaution due to his rare condition. More support is needed to help coordinate care and to follow care plans to prevent unnecessary admissions. Care coordination will be key for people living with rare conditions, especially as more care is being delivered across specialist services, local hospitals and community services.

KH described the stress of being in the phone queue for his GP's surgery then told there are no appointments when he eventually gets through. This is an access issue and any suggestions for improvement can be complex and expensive. The NHS is a massive complex system - how do we get a more integrated NHS and improve communication?

KLB described the importance of understanding symptoms relating to rare conditions. For example, excessive hunger is part of her son's condition and this requires understanding, support and specific advice.

CL shared how she didn't feel confident in community services years ago, but things have come a long way. Resources and funding need to be in place for this to be safe for everyone. She described how her local area is using portable x-ray machines in the community which have resulted in fewer trips to A&E. They estimate this has saved 700 bed days in three months, according to hospital staff from Derriford Hospital in Plymouth.

“If we can't get enough defibrillators into communities, how can we implement adequate community healthcare?” – KLB

JG said this shift could be really useful for people that live further away from their hospital. This could also overcome issues for people who may have to travel for work for long periods of time.

Patients could have a file that they obtain from their designated specialist with the important information about their person-centred care, which they can then show the healthcare professional that is caring for them. This could help to create consistency and prevent people having to explain their medical needs multiple times to different specialists. This could be particularly useful for someone whose first language is not English.

TREATMENT TO PREVENTION

Workshop participants explored the meaning behind this shift and felt it focussed on behaviour changes so that people can live longer, healthier lives. This may help for things like addiction to alcohol, drugs and tobacco and treating and preventing general obesity. However, things are more complicated for people living with rare conditions. Many rare conditions are not preventable and despite behaviour changes, many of these conditions will continue to progress and may impact quality of life and limit life expectancy.

We have seen in some rare conditions where people can't get access to treatments that work effectively and prevent symptoms from progressing. One example is the weight loss injections which have been found to be effective for conditions such as Alström Syndrome, as they support weight loss, help with the management of diabetes and have protective factors for the heart and liver. The demand for these injections is increasing due to the weight loss factor, which is causing major issues with the supply.

SH talked about the trust that people have in the information that is provided. There is often conflicting advice which reduces people's trust. Healthcare information needs to be consistent to build trust. She explained that older people in her community regularly turn to TikTok for information and how there is so much misinformation there. People are not trusting information provided by healthcare professionals but often trust what they find on social media.

“Could healthcare professionals use TikTok to get information across to the public?” – SH

KLB suggested that perhaps people feel dictated to and often find social media more relatable.

LF agreed and said that information on social media is often presented as part of a lifestyle, rather than being prescriptive.

KH also shared concerns about TikTok. He feels a lot of communities don't trust the government and NHS and are therefore vulnerable to fake news. He highlighted how government messaging, behaviours and fake news contributed to the reduced vaccine uptake in Bradford during the pandemic.

No community is hard to reach, and we need real focus on behavioural changes. Some programmes are working well but we are not showcasing some of the good work that is already happening in the country.

KH raised concerns about the number of vape shops open and how many young people are using them. It's the same for places selling unhealthy, low-cost fast food. This is particularly happening in communities living in poverty and experiencing health inequalities. What is being done about this?

Participants discussed prevention initiatives related to screening and how some people are fearful of this as it may highlight their risk of cancer for example. More needs to be done to address fears, provide appropriate support and improve communication.

“We need to ensure that individuals make informed and autonomous decisions about whether they access screening. Information should be available in different languages and accessible to all with varying communication needs.” – JG

SH suggested information should be targeted with advice and sensitive information provided for younger people. She also suggested that we should be having open and honest discussions about health, genetics and screening with young people and within communities.

BDB has been working alongside trusted leaders within communities to deliver creative workshops called **‘Genes, Family History and Your Health’** within diverse and marginalised communities in West Yorkshire.

The workshops use arts and crafts to share basic information about genetics and genetic inheritance. People create their own piece of artwork that they can take home to share with their families (*pictured below, art-work example*). BDB also signpost people for additional support and connect them to healthcare professionals, patient organisations, support, and community groups where possible. Uptake of these workshops has been fantastic, and there is such an appetite from the community to learn about genetics.



DS explained that behaviour change isn't just about education, there is also a psychological impact. There are many grassroots organisations we could be tapping into.



Key takeaway messages

- New Technology and AI should not replace high-quality human interaction and connections
- There is a real worry that technology developments could create further marginalisation
- Opportunity for Community Champions and Connectors to bridge the gap and help communities thrive
- Concerns around assumptions and stigma and the need to understand a person's individual needs and their conditions
- Many conditions, including rare conditions are complex and not preventable – information is often inappropriate and not personalised
- Trust is still a big issue for many communities which impacts access to services and support, including screening
- The need to learn from examples of good practice
- Any new developments should be accessible, equitable, inclusive and meet the needs of our diverse population
- Involve people with lived experience right from the very beginning
- Prioritise inclusive engagement with people from diverse backgrounds
- Lived experiences can help shape future health care services, particularly around access, trust, and culturally competent care
- Making sure that people most affected by health inequalities have a voice in shaping the system

THANK YOU

Representatives from the DHSC Rare Diseases team thanked everyone for such an honest, open and fruitful discussion. Findings from this workshop will feed into the governments consultation and will amplify the voices of people with lived experience in the 10-Year Health Plan.

ASUK and BDB would like to thank everyone who contributed to the workshop, and all members of the BDB Experts by Experience Advisory Group for sharing their insights and experiences and for their continuous support.

We also give thanks to the DHSC and delivery partners for the efforts being made to address health equity for all people affected by rare conditions. We appreciate the recognition given to the importance of the patient voice, including the voices of people who often go unheard.

Finally...

If you would like to know more about the work of Breaking Down Barriers, including how to be a member of our network (it's free to organisations) or if you would like support from our Experts by Experience Advisory Group, please get in touch with Catherine Lewis, catherine.lewis@alstrom.org.uk you can also find more information on our website: www.breaking-down-barriers.org.uk



REFERENCES



UK Rare Diseases Framework

<https://www.gov.uk/government/publications/uk-rare-diseases-framework>

2022 Focus Group Report

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