



Co-producing accessible information to support health literacy

A Guide

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Published 2022

Introduction

This guide is about how to create and use accessible information to support health literacy. Accessible information is the term used for material which is presented in formats that give more people an equal opportunity to understand everyday information.

The learning in the guide is from a project to co-produce accessible information about the uses of routinely collected patient health information in health care research and planning.

The Understanding Patient Data website hosts the accessible personal health information created by the project participants.



Explaining patient data in an accessible way

There is an easy-read guide in both English and Gujarati, and there is also a talking text video where where the narrator, Josh, who has autism, reads out the guide.

These guides have been designed for—and with—people who have additional communication needs but they will also help as an introduction for anyone new to this issue.



Introduction

The project was a partnership between [Thinklusive](#), [Understanding Patient Data](#) and the [Centre for Ethnic Health Research](#). It involved two groups of people, in Suffolk and Leicester. From 2021 to 2022, participants co-produced a set of easy-read materials to support information already available at Understanding Patient Data's website. These more complex materials are inaccessible to some readers.

The twenty-five participants included people with learning disabilities, autism, sensory and physical disabilities, support workers and family carers. In Suffolk there was also a sign language interpreter.

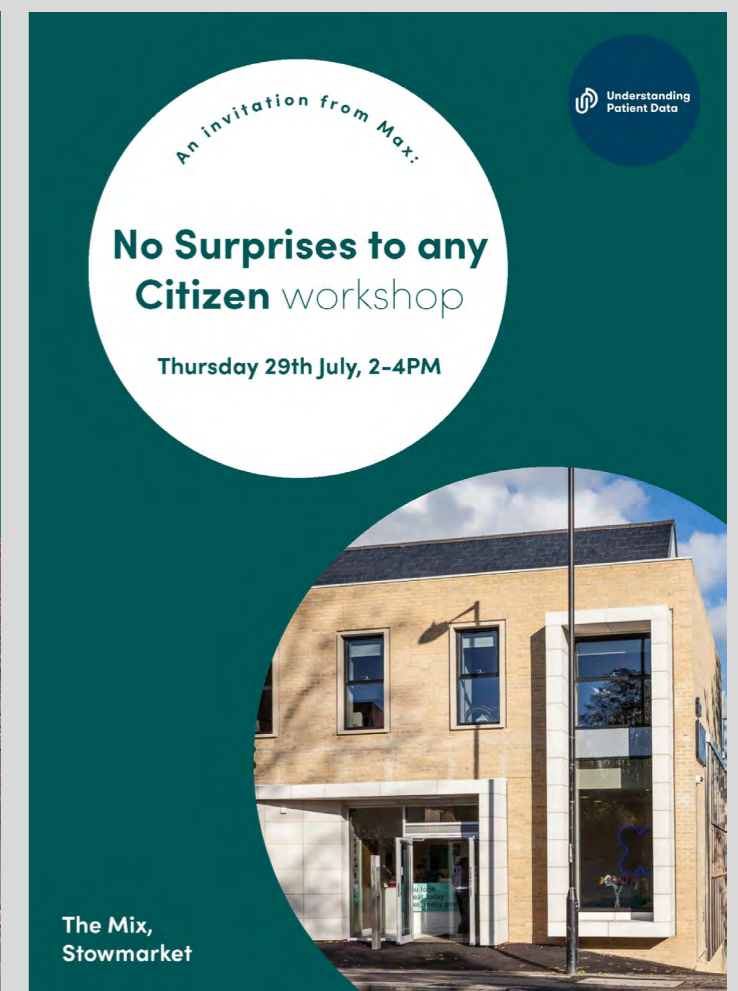
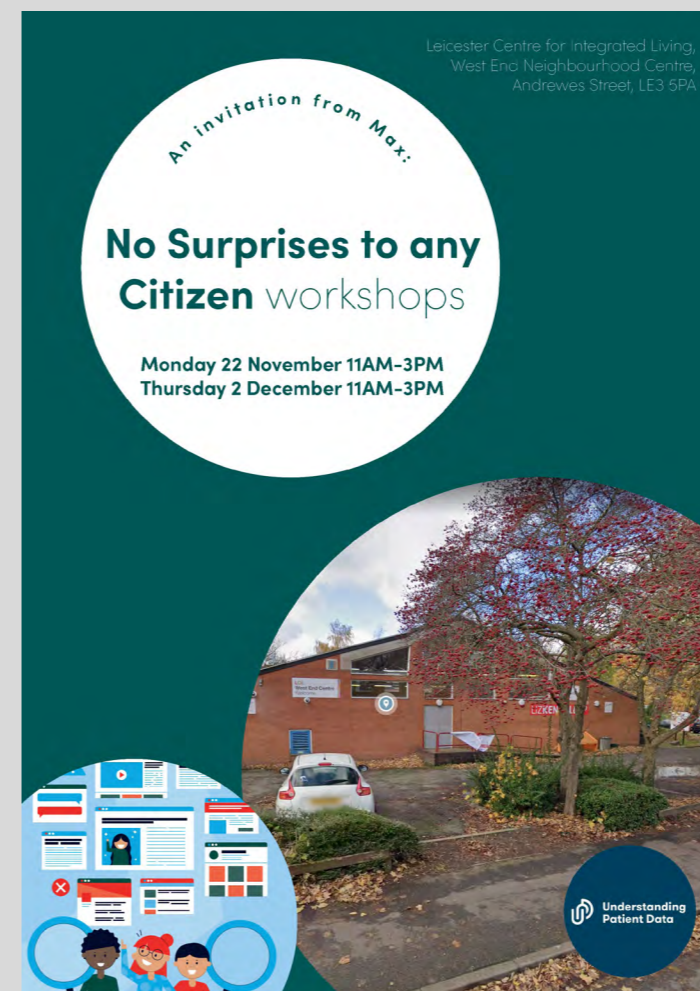
In Leicester, the Centre for Ethnic Health Research provided Gujarati language interpreters. A participant from India joined our online workshops. Her daughter in Leicester participated in person and interpreted for her mother.

This guide focuses on useful, transferable advice, rather than being a detailed account of the project itself. It aims to support best practice in co-producing accessible information on complex health issues, including about patient data.

Introduction

Max Clark and Paul Charlton of Thinklusive were the project leaders and are the guide authors. Max established [Thinklusive](#) in 2018 to support the creation of information that is accessible to all.

We called our project *No Surprises To Any Citizen*.



Invitations to our workshops in Leicester & Suffolk

A participant from the
Leicester co-production group



Our participant groups in Suffolk (above) & Leicester (below)

Key learning points summary



When health researchers and planners want to use personal health information, everyone has the right to know why and to be assured that it is safely used.

The Caldicott Principles include guidance on ensuring 'no surprises for patients and service users'.

By using accessible information design principles, disabled people who need support to understand personal health information use are included in the right to know.



Accessible design techniques support the learning disability and autism communities to understand information. They also support understanding by the general reader.

They require expert input which should be budgeted for in project planning.

These techniques also assist successful co-production by supporting equality of participation.

To generate equality of participation and successful co-production:

- The learning environment will be accessible in its physical and sensory design. Individual learners are supported with disability related adjustments.
- The process will be linguistically and culturally inclusive.
- Identify some personal information about participants beforehand to ease early interactions.



Easy-read materials assist the general reader but do not in themselves always lead people with a learning disability to better understanding.

This will happen when a reader is supported to go through the easy-read document.

They work best for individuals when the person using them is personally connected to or is interested in the content.



Co-production should be at the heart of projects with people with a learning disability and/or autism.

Online workshops can enhance an accessible meeting environment for people with learning disabilities or autism.

Be sure to support individuals who are less confident digitally.

Sharing control over the process of knowledge gain can have pleasingly successful results.



Adults with a learning disability can successfully access sophisticated learning materials when adapted.

Putting critical thinking at the centre of learning design works well for many people.



Discussions about personal health information resonate so much more emphatically when they are shown to be personally relevant.

However, discussing issues related to personal and family experiences may cause participants emotional distress so great care is needed.



The process of co-producing benefits the participants and everyone associated with a project: project leaders, support workers, interpreters, family members and friends.

Insights from participant's experiences as ordinary citizens are powerfully released and shared.

These co-production insights do not just guide the project. They create the project and deliver it more successfully to the intended audience.

Key Learning

Point 1: Background

The National Data Guardian's (NDG) role was created in November 2014 to be an independent champion for patients and the public when it comes to their confidential health and care information.

The NDG purpose is to build trust in the use of data across health and social care and is guided by a number of principles, one of which is to ensure there are no surprises to the public about how their health and care data is being used and what choices they have about this.

These principles are called the Caldicott Principles and the 'no surprises' principle became the eighth Principle in 2020. (No surprises - GOV.UK)

No Surprises to Any Citizen was the challenge set by this project. Information about the use of large data sets in personal health and care is often inaccessible. We aimed to narrow the gap in understanding for communities needing accessible information.





A participant from the Suffolk co-production group

Background

The late Dame Fiona Caldicott, as the National Data Guardian for Health and Social Care at the time, wrote to support the project intention – saying to potential funders in December 2020:

“I was pleased to hear about this project and strongly support its aims. It is vital that we make every attempt to reach all audiences when we’re having important conversations about data and its value.”

“Data is a complicated topic, and so taking steps to tailor those conversations and the language we use, to better help some audiences understand, is an admirable aim. I do hope that this project is granted the funding that will allow it to proceed.”

Understanding Patient Data (UPD) is a well established source for information translating the nature and use of patient data for a general public understanding.

UPD welcomed and funded the project.



When health researchers and planners want to use personal health information, everyone has the right to know why and to be assured that it is safely used.

The Caldicott Principles include guidance on ensuring 'no surprises for patients and service users'.

By using accessible information design principles, disabled people who need support to understand personal health information use are included in the right to know.



The Eight Caldicott Principles
GOV.UK



Participants from the Leicester co-production group

Key Learning Point 2: Accessibility

Accessibility concerns do not apply only to communicating information generally.

Our project was concerned with people who needed communication support adjusted to a specific disability, to the physical environments where the information was shared and with a linguistically and culturally appropriate focus.

Our project introduced accessible communication and environmental adjustments as well as a linguistic and cultural awareness to its processes.

Participant recruitment, for example, was via people, situations and environments familiar to the participants themselves.

This accessible communication and cultural awareness continued right through the in-person and online co-production sessions to the final easy-read outputs of the project.



Accessible information

All organisations that provide NHS care and / or publicly funded adult social care are legally required to follow the Accessible Information Standard.

The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.



Read more about the
Accessible Information Standard



The charity Sense has developed an animated video which provides a step-by-step overview of the Standard. The video includes subtitles and BSL interpretation.



Click the white box to
play the video

Accessible information

Accessible Information means creating information and communications in simplified formats, involving clear words and often imagery.

Focused on the end user, it can include audio, video, simplified text, easy-read, large print and colour contrast alternatives amongst others.

This is an expert resource which has to have funding allocated to it in a project funding plan.

Accessible information will allow for a greater understanding of the work for:

- **Any member of the public**
- **People who are not familiar with the work**
- **People with learning disabilities**
- **People with literacy difficulties**
- **People with autism**
- **People who have dementia**
- **People experiencing poor mental health**
- **People experiencing cognitive difficulties as a symptom of a chronic condition**
- **People with visual / hearing impairments.**

Accessible information

You can find accessible information design resources at AbilityNet.



AbilityNet

Accessible Information design resources

AbilityNet's free online resources and a network of over 300 community-based volunteers help individuals with any disability, of any age, to use all kinds of digital technology.

Accessible language and culture

Our project brought together participants with hearing impairment, some for whom English was a first language as well as many in the Leicester group whose first language was Gujarati.

Most of the project participants also needed disability related support with communication.

In Suffolk, a British Sign Language (BSL) interpreter supported a hearing-impaired participant. We also had a qualified Makaton tutor and experienced person-centred thinking trainer and a trainer in sign-supported English.


In our Leicester workshops personalised working included ensuring that recruitment to the project was done by the Centre for Ethnic Health Research. A Centre staff member recruited the participants and became a co-facilitator in the sessions.

As a result, the Leicester based sessions had closely knit participant, family members and support worker involvement. This was a bi-lingual involvement with Gujarati and English both spoken in the workshops and versions of the easy-read guide co-produced in Gujarati and in English.

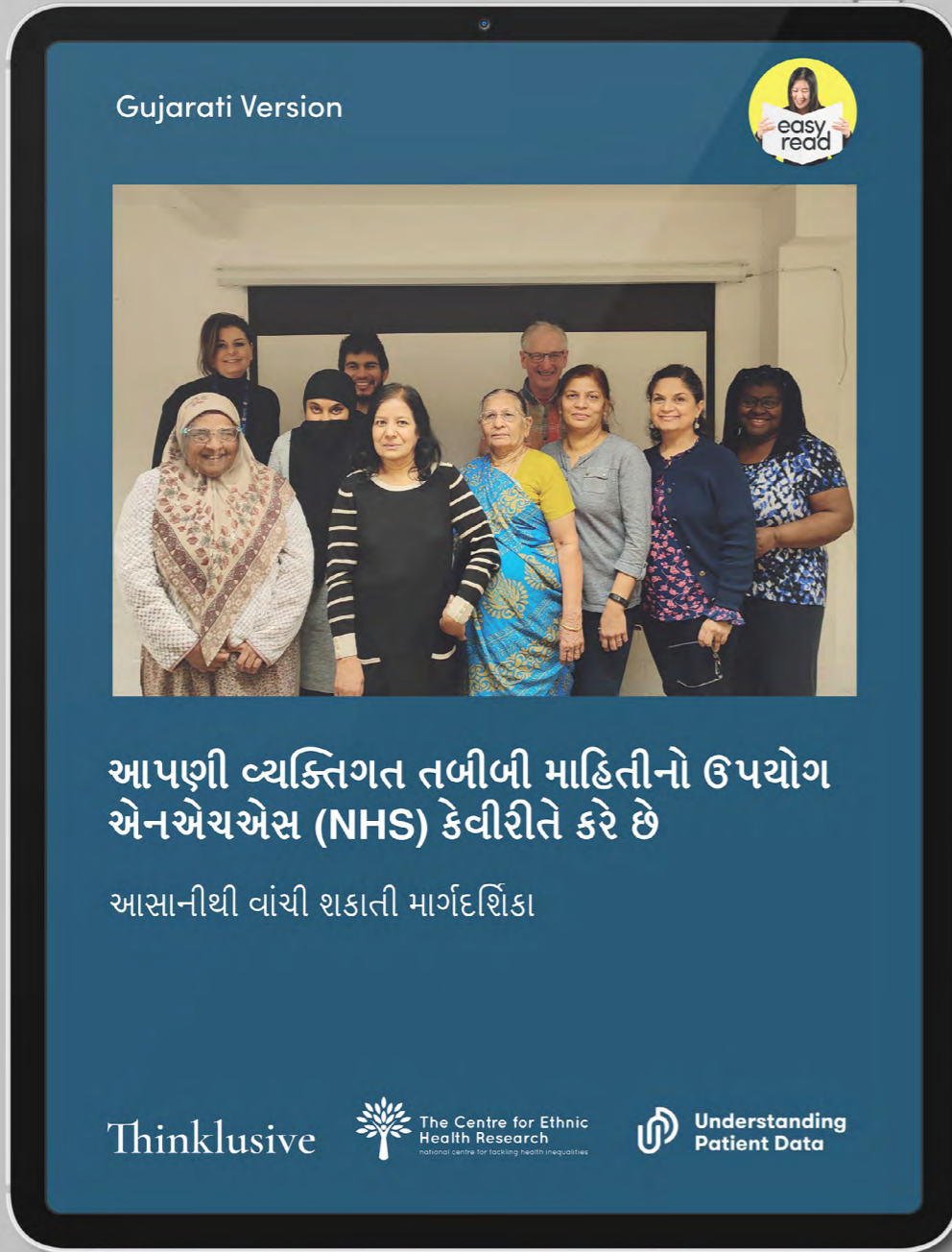
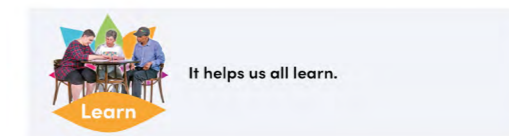
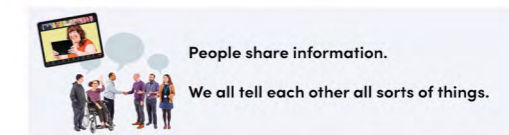
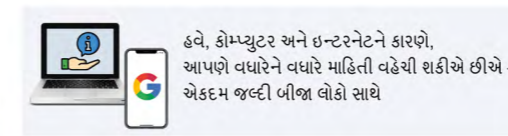
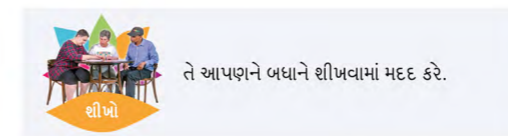
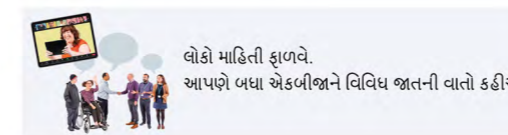
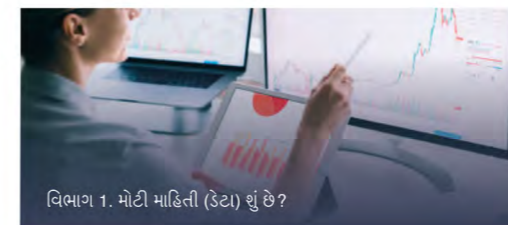
Accessible language and culture

The Centre for Ethnic Health Research costs were part of the project funding application.

In 2022, the NIHR Applied Research Collaboration East Midlands published a toolkit entitled: Increasing participation of Black Asian and Minority Ethnic groups in health and social care research.

 Increasing participation of Black Asian and Minority Ethnic groups in health and social care research

This toolkit aims to capture best practice and provide researchers with a framework on how to improve the participation of Black, Asian and Minority Ethnic groups in research. We advise using this toolkit for similar projects.



The front cover of the Gujarati easy-read digital guide

A page from the easy-read guide in both English and Gujarati

Accessible environments

There were several autistic participants in both groups. One participant used an electric wheelchair. This meant that we needed to be aware of physical and sensory accessibility at face to face workshops.

A newly built youth centre in Suffolk had accessible parking and internal movement design giving straightforward physical access for our participant's wheelchair use.

To ensure an autism accessible environment, think about visiting workshop rooms beforehand to check for suitable lighting, sound echo and size. A good room will have lighting that does not flicker, isn't too bright, echoey, too big, has soft carpeting, is comfortable and has a break-out area. Ensure that equipment, speakers, projectors, screens, etc work efficiently.

If you know a little about the participants beforehand, you will be able to tailor the event to their personal access needs, in addition to making any necessary disability adjustments. By asking a pre-course question such as, "Do you have a favourite interest or sports team?", the organiser can lead a participant to an easier comfort on the session day itself.

Accessible environments

In Leicester, one of the autistic participants was a great fan of the local rugby club. This kind of individual level information, if known beforehand, can help the flow of conversation where there is autism related hesitation to engage with a new experience at the start of a workshop.

Inclusion

Our project's intention was to include participants in a discussion about the importance of understanding the uses of routinely collected health information.

'To include' is a hard intention. For us, it was to reject the exclusion of people with communication related disability from participation in public discussion. More broadly, inclusion as an intention now widely informs health and social care organisations' policies and operations.

Our project benefited from the population and project specific approach described in the National Institute of Health and Care Research guide: ['Improving inclusion of under-served groups in clinical research'](#).

2

Accessible design techniques support the learning disability and autism communities to understand information. They also support understanding by the general reader.

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To generate equality of participation and successful co-production:

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- The process will be linguistically and culturally inclusive.
- Identify some personal information about participants beforehand to ease early interactions.

See the National Autistic Society guide:



See the National Autistic Society Guide: Sensory differences - a guide for all audiences

Be guided by the NIHR's publications:



Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project



Increasing participation of Black Asian and Minority Ethnic groups in health and social care research

Key Learning Point 3: Using easy-read

“If you can’t write it in an easy-read, you don’t understand it yourself”

This is a quote from a blog by the Scottish Council for Learning Disability exploring the extent to which easy-read information helps understanding. It concludes that easy-read is not a magic wand but is likely to support understanding when the individual has help to use it.

Easy-read is only one of the ways to communicate with people who have learning disabilities, and it does still require people to have a reasonable level of literacy. When, however, the easy-read document gets things right, it can be a big help to a general reader’s understanding as well as when the person is being supported to read and understand the document.



Using easy-read

The project workshops presented information in easy-read PowerPoint presentations but they were only the starting point for our discussion.

The workshop leaders continually went to each person in the group, checking understanding. We investigated their understanding both in relation to the workshop materials and also beyond to participants' family life stories.

For example, in one session we looked at how to weigh up the evidence about claims people come across in the media. We discussed an advertising claim that black charcoal in toothpaste helps with cleaning teeth. A number of people in the Leicester workshop described their own use of charcoal toothpaste for cleaning teeth – as well as recounting a family history in India of actual charcoal use. This observation was directly relevant to assessing the evidence base for the truth of the advertisement.

In this example, the participant engaged more successfully with the discussion because she connected to her own experience and to a family history. This ability to connect to the subject through personal experience, or by its relevance to the reader, applies to using easy-read materials.



Easy-read materials assist the general reader but do not in themselves always lead people with a learning disability to better understanding.

This will happen when a reader is supported to go through the easy-read document.

They work best for individuals when the person using them is personally connected to or is interested in the content.

Key Learning Point 4: Co-production

The purpose of our project was to remove the barriers to understanding personal health information use for the learning disability and autism communities.

Our approach was twofold. Firstly, in our co-production workshops, we used accessible information in adapted learning environments. Secondly, we co-produced the project activities and outputs.

The Think Local Act Personal National Co-production Advisory Group says the following about co-production:

“Co-production is not just a word, it is not just a concept, it is a meeting of minds coming together to find shared solutions. In practice, co-production involves people who use services being consulted, included and working together from the start to the end of any project that affects them.”



Co-production



Think Local Act Personal
What is co-production?

Co-production is described well elsewhere, so this guide need only signpost to them. Some references are: ImROC, an independent consultancy:



Co-Production – Sharing Our Experiences,
Reflecting On Our Learning

The Social Care Institute for Excellence has a co-production network page linking onto many other co-production information sources:



Social Care Institute for Excellence
Co-production Network

The project adopted a co-production approach to complement reliance on accessible information techniques.

Workshops in-person and online

We had planned to have all the workshops in person but unfortunately the Covid-19 pandemic prevented that. Instead, we had some workshops with everyone in the room, some entirely online and some as hybrid – with people in the room and online.

Holding workshops online did though lead us to create the text content of the easy-read documents in a more accessible way.

In our online workshops we invited participants to study each word and sentence and image of the easy-read material in production. This highlighted both individual and group preferences when it came to content and design.

The risk of autism sensory overload in doing this detailed work was greatly lessened in the online sessions. This is because each participant had their own prepared personal space and there was much less stimuli from the screen than would have been the case in the workshop room.

Personal relationships had already developed in the previous in-person workshops, making for confident interactions, and participants could come in and out of the conversation at will.

Workshops in-person and online

These positive aspects of online use for accessibility are confirmed by [I AM](#) – a charity working with and supporting a wide range of people, aged 10 years and upwards, who have a diagnosis of Autism Spectrum Condition (ASC).

They say about the pandemic driven experience of using Zoom (October 2020):

“Here at I-AM, to stay connected with our members, we have been running highly successful Zoom meetups...

Our meetings are led by our members, we are committed to co-production, there is no expectation of convention or direction around topics of conversation. Essentially our members are in the driving seat. Often for ASC individuals, this is a rarity in itself with the pressure of having to put on the mask of conformity.

Ownership for the sensory environment is retained by the individuals, there is no judgement going to be made if the compulsory bookcase is not in the background or the need for a pot plant to be staged for aesthetic effect.”

Sharing control

Moving from no understanding of patient data to an enlivened understanding happened by supporting participants to share control of the learning process equally with the workshop leaders. Participants therefore made choices such as determining the schedule for the day, by, for example, creating time for a break for prayer.

It also caused a complete change in how we used the existing Understanding Patient Data video animations as a way into our discussion. As a result of this shared control participants were lively, motivated and engaged.



Zoom meetings and Autism



Co-production should be at the heart of projects with people with a learning disability and/or autism.

Online workshops can enhance an accessible meeting environment for people with learning disabilities or autism.

Be sure to support individuals who are less confident digitally.

Sharing control over the process of knowledge gain can have pleasingly successful results.



Key Learning

Point 5: Health literacy

Our in-person workshop discussions were about how we can have more confidence in assessing whether or not the information we are given is trustworthy. We developed an approach to trustworthiness using the Sense about Science Evidence Hunter Activity Pack.

A series of activities led by a group leader to develop participants' critical thinking about claims they come across in day to day life.

Our project's approach was to assert that learning disabled and autistic adults are capable of sophisticated learning, just like any other non-specialist citizen. We created a rights-based workshop culture that challenged any exclusion of our project's disabled participants from acquiring knowledge of patient data.

To achieve this, we adopted a three-stage process. These three stages were to develop participants' critical thinking abilities through media literacy, then through health literacy and finally through patient data literacy.

Health literacy

Media literacy involves applying critical thinking skills to the messages we receive through mass media. It allows us to recognize the influence media has and gives us the knowledge and tools to navigate its impact.

Health literacy relies on the combination of different skills needed to access, understand, appraise, and apply health-related information from multiple kinds of sources – including large patient data sets like the UK's Cancer Registries.

People with good health literacy make more beneficial health-related decisions and manage their chronic diseases better than people with low health literacy.

[The importance of health literacy for self-management: A scoping review of reviews](#) (van der Gagg et al Sage Journal Chronic Illness 2020).

The Suffolk participants were invited into the project from a health literacy group. Our project focussed on how media literacy together with health literacy provide the combination of different skills needed to access, understand, appraise, and apply health related information from multiple kinds of sources – including large patient data sets.

Health literacy

In other words, the project participants were tasked with exploring the assertion made by policy makers, scientists and clinicians that using patient data for health research and planning is for our own good and also for the good of our families and neighbours.

How do we know if that it is true? And how can the existing Understanding Patient Data sources of information be adapted by a participant group that includes adults with a learning disability and/or autism?

We adapted the Sense about Science's Evidence Hunter Pack by making its materials more accessible to our learners in the workshop slides and activity materials design. We closely held participants, however, to the concept of well-sourced evidence and thinking critically about the reliability of those sources.



Adults with a learning disability can successfully access sophisticated learning materials when adapted.

Putting critical thinking at the centre of learning design works well for many people.

Key Learning Point 6: 'Stories from the Heart'

The Understanding Patient Data ['Data Saves Lives'](#) videos were a 'perfect' tool to generate access to patient data discussion.

The emphatic conclusion, however, was that the narrative captions and dialogue supporting the videos did not use accessible language, as measured both by the response of workshop participants and their family members with supported communication needs.

The videos also generated considerable emotional discomfort which we had not anticipated and so had not prepared for. This was because health conditions that featured in the videos, such as heart disease, cancer and strokes, had been experienced by some of the participant families and had caused lifetime disability and death. Having witnessed this emotional impact, we changed the way the video materials were used. We moved from only video led stories to a combination of video and participant led lived experience stories as a means to interrogate patient data use in health care research and planning.



‘Stories from the heart’

This is how Mary-Lou, another participant, described her experience when watching the video about patient data and a heart attack:

“In July/September (not 100% on date) 2021 I was on zoom with Max and Paul in the session which Joel called ‘Stories from The Heart’. We were shown a YouTube video of information on someone having a heart attack, but weren't warned of what the video was, prior to watching it. My 1st reaction was to slam my laptop lid down and storm off but I didn't...I just turned off the camera and sound on my laptop and then got up and got some juice, sat there and cried (I didn't see any of the video). Once the video had stopped, I wiped my eyes and then put my video and sound back on so I could be seen.

So why did I cry?

I cried when the project left the ‘dry’ compass of ‘what is’ patient data and tracked its way into the ‘why’. We were using the Understanding Patient Data videos of health conditions connected to routine patient data collection. They describe ‘why data saves lives’ through cartoon videos where stories of cancer, dementia, stroke and heart attack are unpacked.

I was in my own home, joining online. The video took me back to 27th July 2015 at 3.55pm...my mum had a heart attack and died in the house a few metres from where I was doing my zoom...my mum had a heart attack and died, here.”

‘Stories from the heart’

Mary-Lou, and everyone else in the groups, had expressed personal and sometimes very difficult experiences of understanding why we routinely collect patient health information.

These experiences, when expressed in the workshops, enlightened the patient information discussions.

The subsequent workshops benefited from our prior learning. They had a safer, planned, discussion space so that disclosure of personal and family experience did not give rise to the same distress as previously.



Discussions about personal health information resonate so much more emphatically when they are shown to be personally relevant.

However, discussing issues related to personal and family experiences may cause participants emotional distress so great care is needed.

Key Learning Point 7: Participant feedback

There was powerful feedback about the pleasure felt by the participants at having been invited into and successfully taken part in a sophisticated learning project.

They felt proud about their new understanding of the uses of personal health information for health research and planning. The easy-read booklets produced through the workshops have the photos of the participants who wanted to be photographed on the front page.

[This video link](#) is to Sharifa and Rachida from the Leicester group. Please use the video subtitle assist when watching it. Sharifa and Rachida reveal the strength in co-creative working, their words exclaiming their satisfaction in knowing they created the content of the project documents. As well, they assert their new understanding of the use of personal health information with Sharifa saying:

“What I liked about the session is that it is interactive, got to meet a lot of different people, there’s a lot of information that I didn’t know before that, that I was glad I learned.”



Participant feedback



Mary-Lou, an artist and disability rights activist, said:

***“Being part of making things like this easy-read will hopefully help someone else have a better outcome in my situation.*”**

I also know when you are faced with that pressure of life and death all sense goes out the window so easy read would be good for just anyone in my opinion.”

Participant feedback

The importance to participants of having co-produced the project cannot be overstated.

There was repeated request from participants for hard copies of the project materials to bring back to their homes. The purpose of doing so was to evidence to families the fact of their original creativity in co-producing our complex project.



The process of co-producing benefits the participants and everyone associated with a project: project leaders, support workers, interpreters, family members and friends.

Insights from participant’s experiences as ordinary citizens are powerfully released and shared.

These co-production insights do not just guide the project. They create the project and deliver it more successfully to the intended audience.

8. Conclusion

In our Suffolk and Leicester workshops our participants revealed how personal and family stories can connect with the broader issue of how health data is used and can encourage enlivened understanding. This is even when, as with our project, we co-produced the outputs from a starting point of media and health literacy approaches.

Critically thinking about how personal health information is used, its sources and the evidence relied upon in health research and planning, all resonate so much more emphatically when those issues are shown to be personally relevant, when linguistically and culturally appropriate, and when explored through each one of us as Stories from the Heart.

Why so convoluted an approach you may ask? Our project was quite simply ambitious. We did not just want to 'drop' an easy-read booklet into the Understanding Patient Data landscape. We were determined that every participant's experience generated real understanding to the extent urged upon us by the late Dame Fiona Caldicott in her letter of support to us:

"I was pleased to hear about this project and strongly support its aims. It is vital that we make every attempt to reach all audiences when we're having important



Conclusion

Together with our workshop participants, we directly challenged the access barriers to understanding in communities where communication support is needed.

And everyone had fun overcoming them.



9. Project outputs and dissemination

This link is to the project's accessible resources:



New resources: explaining patient data in an accessible way

There is an easy-read guide, available in both English and Gujarati and there is also a talking text video where the narrator, Josh, who has autism, reads out the guide.

These guides have been designed for—and with—people who have some additional communication needs but they could also be helpful as an introduction for anyone new to this issue.

We want these resources to be used by teams that need to communicate the way patient data is used to a range of different audiences, so like most of our work, they are available under a CC-BY license.

The project material has been well received with comments including:

“...as a person who relies on accessible resources, this is absolutely brilliant!”

Project outputs and dissemination

“What super work... I will share with comms colleagues and with my content designer who will find these resources really interesting.”

“This is great – well done!”

“Thanks for these, they look great. We’d love to share them via our networks.”



Thank you and acknowledgements

Project participants

Thank you to our project participants in Leicester and Suffolk.



Ace Anglia

Thank you to Ace Anglia who facilitated participant recruitment to the Suffolk workshops.

<https://www.aceanglia.com>



Angharad Williams, NIHR Clinical Research Practitioner

Angharad supported the recruitment of participants and the delivery of the workshops. Angharad is a Clinical Research Practitioner at West Suffolk NHS Foundation Trust with a background in science and experience of working in research delivery with adults with learning disability.



Barbara Czyżnikowska

Barbara is a Community Engagement Officer at the Centre for Ethnic Health Research. She facilitated the entirety of the Leicester activities.



The Centre for Ethnic Health Research

Thank you to the Centre for Ethnic Health Research who enthusiastically and very effectively supported the project in Leicester.

The Centre for Ethnic Health Research vision is “to reduce ethnic health inequalities”.

It does this by working with patients, the public, community and voluntary sectors, researchers, health and social care organisations. Its work includes facilitating the creation of materials which are culturally and linguistically appropriate in respect of different ethnicities.

<https://ethnicealthresearch.org.uk/>



Kate Chate, Family Carer

Kate supported the delivery of the workshops as a family carer and as a makaton user. Kate is a family carer whose son has autism and learning disability. She is a qualified Makaton tutor and experienced person centred thinking trainer and a trainer in sign supported English. She is an Associate Family Consultant with the support organisation Dimensions UK.



Sense about Science

Thank you to Sense about Science whose Evidence Hunter Activity Pack, published in January 2019, was an invaluable source of material and inspiration to the project design and delivery.

<https://senseaboutscience.org/>



Suffolk Artlink

Thank you to Suffolk Artlink who facilitated participant recruitment to the Suffolk workshops.

<https://www.suffolkartlink.org.uk>



Understanding Patient Data

Thank you to Understanding Patient Data who funded the No Surprises to Any Citizen project and this Guide.

Also, for the use of their series of video animations to explain how patient data saves lives. Following the journeys of patients with cancer, a heart attack, diabetes, dementia and asthma, they show the huge range of ways data is used to improve care, and the safeguards that are in place to protect confidentiality.

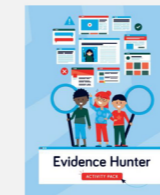
<https://understandingpatientdata.org.uk/>

11. Appendices

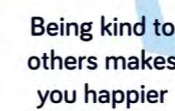
Examples of easy-read slides from our first workshop.



Welcome to the first 'No surprises to any citizen' workshop.



Today, we will be working through the Evidence Hunter activity pack.



Today's activities are designed to give you the opportunity to explore claims you come across.

These could be:



online



in the news



in adverts



talking to family and friends



We will be looking at claims and evidence.



Can anyone tell us what a **claim** is?

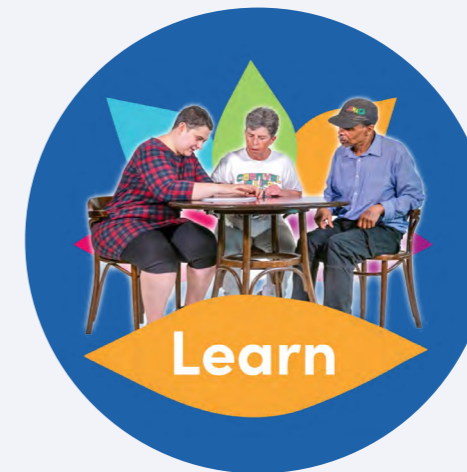
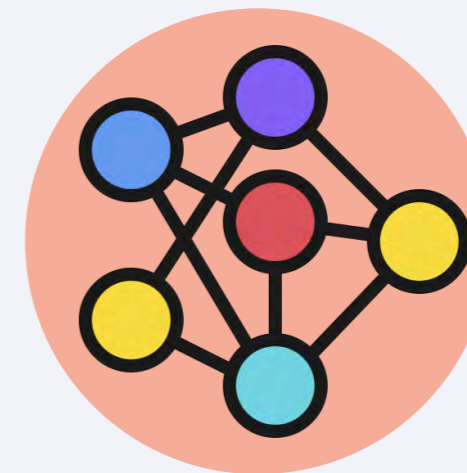
Can anyone tell us what **evidence** is?



A selection of imagery used in the project.


Photographs, Photosymbols, icons and symbols can be used alongside simplified text.

With our easy-read slides and guides in this project, we used a combination imagery, licenced from a number of different online image libraries including photosymbols.com, Adobe Stock and flaticon.com





Understanding Patient Data




Our project


Welcome




Max Clark
Thinklusive
Paul Charlton
Patient Research
Ambassador Eastern Region
Angharad Williams
Clinical Research Practitioner,
West Suffolk Hospital
Kate Chate
Family carer





We are working on a project about health.




We want to work with people with a learning disability on this project.




Easy-read guides

Our first step is to set up a meeting after COVID-19 restrictions end.




We would like up to 15 people to meet with us face to face for an understanding health information discussion.




Work together


After this first meeting, we then want to host 3-4 co-production sessions.



These would be to work on some accessible information about health data.




There will be opportunities to tell personal stories and make videos.




For these we would need to talk to you about where the stories/videos will be shared.


If you would like to take part:



Tell me now I will get back to you.



Text Max: 07725 886910



E-mail Max: max@thinklusive.org

Recruitment information for the workshops.



How the NHS uses our personal health information

An easy-read guide

Thinklusive



Understanding Patient Data



Information stored on a computer is called data.



When lots of it is combined together, it becomes big data.

This can help us to see patterns.



Let's look at an example of a big data pattern.



The London Ambulance Service provides care to 8.6 million people.



In 2019 the London Ambulance Service said it wanted to reduce its 68 ambulance stations.



They said they had looked at all of the journeys of all the ambulances going out on a call.



They said the ambulance journeys made patterns.



These patterns showed where ambulances were going and how long they took.



The data showed that 18 large Ambulance Centres would be better than 68 small ambulance stations.



The data showed that with bigger centres, ambulances would get to patients quicker.



This is an example of how collecting information allows us to improve patient care.

Pages from the Leicestershire version of our easy-read guide: 'How the NHS uses our personal health information'

Document co-produced with experts by experience across physical and virtual workshops.



આપણી વ્યક્તિગત તબીબી માહિતીનો ઉપયોગ એનએચએસ (NHS) કેવીરીતે કરે છે

આસાનીથી વાંચી શકાતી માર્ગદર્શિકા

Thinklusive



Understanding Patient Data

અનુક્રમણિકા

01. વિભાગ 1
મોટી માહિતી (ડેટા) શું છે?
02. વિભાગ 2
દર્દીની માહિતી શું છે?
03. વિભાગ 3
દર્દીની માહિતી કોણ જોઈ શકે?
04. વિભાગ 4
દર્દીની માહિતી વાપરવા વિશે નિયમો
05. વિભાગ 5
નેશનલ હેલ્થકેર ડેટાસેટ
06. વિભાગ 6
વધુ માહિતી

Pages from the Leicestershire version of our easy-read guide: 'How the NHS uses our personal health information' in Gujarati.

આ પુસ્તિકા વિશે

01. 02. 03.

અમે આ પુસ્તિકાને આસાનીથી વાંચી શકાય તે માટે અલગ વિભાગોમાં છુટી પાડી છે.

તમે કદાચ તેને તબક્કાવાર વાંચવા ચાહો.



આ પુસ્તિકા વાંચવા તમે કદાચ મદદ મેળવવા ચાહો.

સપોર્ટ



જો તમારે કોઈ સવાલ હોય તો, આ પુસ્તિકાના અંતમાં વધારે માહિતી છે.



વિભાગ 1. મોટી માહિતી (ડેટા) શું છે?



લોકો માહિતી ફાળવે. આપણે બધા એકબીજાને વિવિધ જાતની વાતો કહીએ.



શીખો

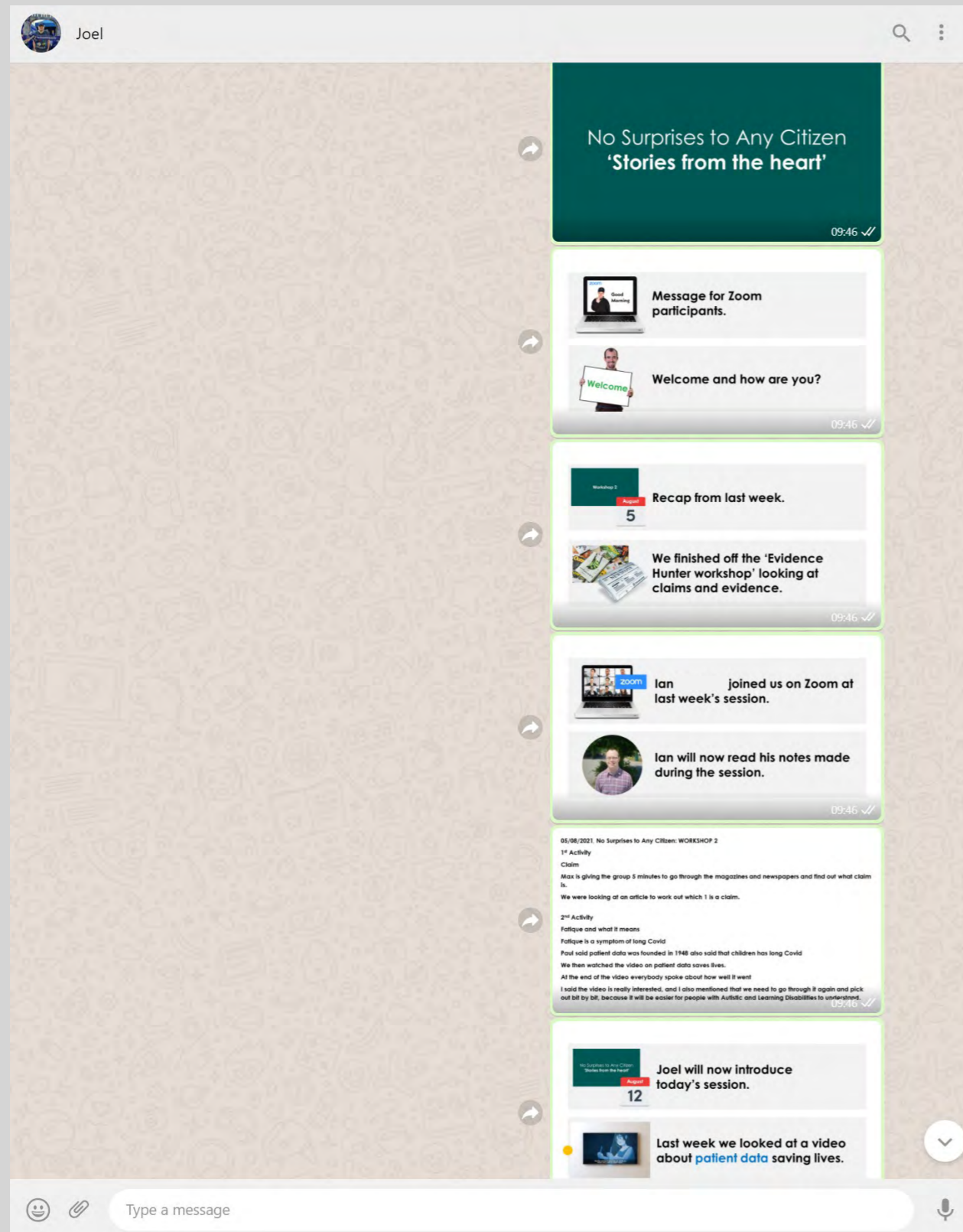
તે આપણને બધાને શીખવામાં મદદ કરે.



હવે, કોમ્પ્યુટર અને ઇન્ટરનેટને કારણે, આપણે વધારેને વધારે માહિતી વહેંચી શકીએ છીએ – એકદમ જલ્દી બીજા લોકો સાથે

Copies of slides sent to participant on WhatsApp.

This visual aid helped Joel to prepare for the session and co-deliver some of the slides.





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